Clonal progression vs. Clonal Initiation in MDS

Solving the clinical challenges of MDS will require a better molecular understanding of two key stem cell transitions. The most well studied is clonal progression—the transition from the clonal disease MDS to acute myelogenous leukemia (AML). Over the past decade an increasing number of research teams (more than can be cited here) has applied molecular cytogenetic studies and systems biology in attempts to define the molecular basis of this type of transition. Some important descriptions of the genetic and transcriptional states of MDS cells have developed, but the most challenging result is that the genetic pathways are both complex and heterogeneous. Consequently, it is not clear that these studies point to novel and druggable molecular targets. Part of the difficulty in developing this kind of information has to do with the fact that not all patients with MDS will evolve to AML. Although this sounds like good news, patients, families, and physicians know too well that the MDS phase itself can represent, in many instances, a huge burden. Few would argue with the desirability of a strategy that could reliably prevent MDS in the first place.

Even if the molecular phenotype of fully established MDS clones were to be perfectly defined, what wouldn’t be at all clear is how they initially appeared in the marrow and how they ascended to take control of hematopoiesis. This second type of evolutionary transition, from what appears to be a normally functioning bone marrow to the emergence of a clone of dysfunctional (MDS) stem cells, is less well-studied. An important explanation is that MDS is not particularly common so a large number of patients at risk would have to be studied to develop informative data. Years ago we reasoned that such studies would be more practical in populations of patients at high risk for the development of clonal evolution to MDS and AML. We chose Fanconi anemia (FA) as a candidate, a rare inherited disease in which the relative risk for AML is nearly 900 and the risk for MDS is even higher. The scientific advances that permitted such studies were the cloning and characterization of at least 13 FA genes.

In vitro and in vivo studies on human and murine cells have persuasively demonstrated that in this disease, the evolution of MDS clones occurs in the context of inherently unfit stem cells and that the evolution of new clones represents a quasi-adaptive response. In our initial studies on the pathogenesis of bone marrow failure in FA, we were most impressed by studies on hematopoiesis in patients with acquired aplastic anemia.
**Acquired Aplastic Anemia and Unfit Stem cells**

Patients with acquired aplastic anemia are at high risk for the development of MDS. In the aplastic state, aberrantly activated oligoclonal T-cell populations suppress hematopoiesis by releasing cytokines (importantly IFNγ and TNFα) that induce apoptotic responses in stem cells and progenitors. The importance of the cytokines in the pathogenesis of the disease has been confirmed in a murine model in which monoclonal antibodies to TNFα and IFNγ prevent fatal aplasia. Stem cells assaulted in this way represent perfect models of a population rendered unfit by an environmental stressor. Failure to eradicate the offending T-cells would favor the evolution of somatically mutated stem cells whose mutation(s) interdicted a pathway of apoptosis incited by the above cytokines. The emergence of the MDS or pre-MDS clone would occur not because the mutation was advantageous in a head-to-head competition with a normal stem cell; it would emerge instead precisely because the mutation was advantageous when measured against a background of highly unfit stem cells (the ones without the somatic mutation).

**Inherited Bone Marrow Failure Syndromes: Role of Cytokines in Selection**

While the bulk of the scientific literature on Fanconi anemia genes and proteins focuses on the DNA damage and repair response, in which the proteins play a key role, it is also clear that the bone marrow failure that occurs in most patients with this disease is pathophysiological related to acquired aplastic anemia. Studies on hematopoietic cells from children with Fanconi anemia and later in mice nullizygous for one of the FA genes, Fancc, demonstrated not only that FA-C cells release more TNFα in the ground state but that the FA progenitor cells are inherently hypersensitive to apoptotic cues, including IFNγ, TNFα, mip1-α, and TRAIL. Some of the mechanisms by which FA cells are hypersensitive to inflammatory cytokines are being clarified. For example, for TNFα hypersensitivity in FA cells, two effector serine/threonine kinases are important because their activity is influenced by FA proteins. The first is the protein kinase PKR, a key molecular effector of the anti-viral response and the second is the apoptosis signal regulating kinase 1 (Ask1).

Although the experimental evidence supporting stem cell stress in inherited marrow failure syndromes other than FA is not as robust, evidence is beginning to emerge supporting the idea that the heterogeneous inherited mutations result in higher rates of stem and progenitor cell apoptosis. These pools of damaged stem cells are all perfect environments for the selection of somatically mutated stem cell clones that have acquired the capacity to completely ignore apoptotic cues. These clones will have a huge competitive advantage when compared to the highly disadvantaged reference population of stem cells. Therefore it is likely that in all aplastic states the coefficient of selection for clonal evolution is very high in the stem cell pool.

**Pathways of Stem Cell Adaptation**

If a new clone is to be more fit, it and its progeny must be resistant to the factors that put the stem cell pool under pressure in the first place. For example, if an aplastic marrow packed with IFNγ- and TNFα-hypersensitive stem cells provides sufficient selective pressure for the emergence of a fit clone of stem cells, the clonal progeny ought to be IFN- and TNF-resistant. Clinical and laboratory observations have confirmed the accuracy of this notion. There are two well established pathways for stem cell adaptation in Fanconi anemia. The first is known as mosaicism, in which a hematopoietic stem cell undergoes genetic reversion, a process by which one of the mutant FA alleles has been corrected in a hematopoietic stem cell. This cell and all its progeny have gained fitness in a perfect (not maladaptive) way. That is, the growth of clonal progenitors can be inhibited by cytokines but only at high doses (in the way normal progenitors respond). In cases in which the entire hematopoietic organ includes progeny of a stem cell corrected in this way, the occurrence of AML/MDS has not been reported, although some patients with incomplete mosaicism (a mixture of unfit and fit [reverted] stem cell pools) can develop clonal evolution in an uncorrected stem cell. These clinical observations are consistent with the importance of the selection coefficient in stem cells. Even stronger evidence exists from systematic experimental studies.

The second pathway of adaptation is not as helpful to the patient because while it assures the survival of the clone, it does so by interdicting pathways that normal stem cells or their progeny need to preserve. In this sense the somatic mutation in a stem cell is maladaptive. We have observed cytokine hypersensitivity in progenitor cells of patients with Fanconi anemia but have found that progenitor cells from their affected siblings who have MDS are resistant. In murine models of FA, while stem cells and progenitors are hypersensitive to a variety of cytokines neoplastic clones are resistant. In fact, the idea that ongoing exposure of FA stem cells to TNFα represented selective pressure for the emergence of MDS clones has been formally tested and has proven to be the case. That is, the replication of murine Fancc null stem cells and their progeny exposed repeatedly to TNFα in vitro is highly suppressed but by maintaining the cells and their progeny in culture for a number of weeks, new cytogenetically abnormal clones can be detected, clones that are leukemogenic in transplanted mice.

**Therapeutic Implications of the Adaptive Model**

It isn’t known whether somatic mutations are formal adaptive mutations (in the sense that geneticists mean when they say adaptive mutations) or whether the cytokine permits the outgrowth of a pre-
existing cytokine-resistant stem cell (cryptic potentially leukemogenic clones are known to occur in normal individuals). What matters most is that if the pressure can be relieved (by reducing the production of the cytokine and blocking the signaling pathways it ignites) the coefficient of selection for a new clone will decline and reduce the likelihood of clonal evolution to MDS and AML.

Is Fanconi Anemia MDS Relevant to More Common Types?

Of the subtypes of MDS encountered in practice, two are notoriously aggressive. The first is tMDS, a disorder that occurs in patients who have been exposed in the past to cytotoxic chemotherapy and radiation. The second is MDS that occurs spontaneously in children and adults with the rare inherited bone marrow failure syndromes (e.g., FA and dyskeratosis congenita). FA-MDS and tMDS share clinical and biological features. In both types, recurring episodes of stem cell damage precede the onset of clonal evolution. Second, the progression to FA-MDS and tMDS is common. Third, marrow cells from both groups exhibit multiple prognostically unfavorable clonal cytogenetic defects. Because alkylation agents are common culprits in tMDS and tAML, we are particularly interested in work published many decades ago clearly established that long-term permanent stem cell dysfunction resulted from repeated exposure to alkylation agents. These reports suggest that a drug-induced reduction in stem cell fitness may underlie the evolution of tMDS clones according to the adaptive model. We also believe that MDS clones from tMDS and FA-MDS patients might be fundamentally similar at a molecular level and are seeking now to validate that notion.

In this, the 200th anniversary of Charles Darwin’s birth, it seems appropriate to emphasize that many principles of natural selection are just as applicable to populations of single cells as they are to sexual populations. Evidence from a vast pool of evidence from genetics, evolutionary biology, stem cell biology, and hematopoiesis leads inescapably to the conclusion that clonal evolution in aplastic states arises in the context of ongoing stem cell damage through a process of clonal selection and adaptation. In the past two years this theoretical paradigm has been validated in clinical and preclinical models robust enough to energize plans for surveillance as well as development of rationally designed leukemia prevention trials in patients with bone marrow failure syndromes. There are many other inherited bone marrow failure syndromes associated with an increased risk of MDS. The insights the scientific community has gained from studies on the molecular pathogenesis of Fanconi anemia persuade us that comprehensive studies on hematopoiesis in these other rare disorders will be just as informative and just as relevant to our goal of understanding more common forms of MDS in a way that will help us design strategies to prevent them.

References


Kathy Heptinstall
Operating Director

Have all of you noticed that the years seem to fly by faster and faster? It seems only yesterday that I met a core group of physicians—Drs. John Bennett, Terry Hamblin, and Franz Schmalzl to begin preparations for the 3rd International Symposium on MDS that was held in Chicago, Illinois in 1994. These men formed the core of thought leaders in MDS who not only defined these syndromes as separate from acute leukemia but who moved the disease knowledge forward and continue to do so today.

Franz Schmalzl and Terry Hamblin supported and guided the first two symposia devoted to myelodysplastic syndromes in Innsbruck, Austria and Bournemouth, England, respectively. A quick fifteen years later we are engaged in the 10th International Symposium on MDS in Patras, Greece under the guidance of Professor Nicholas Zoumbos of the University of Patras.

This bi-annual symposium has been held—between Chicago and Patras—in Barcelona, Spain (1997); Prague, Czech Republic (1999); Stockholm, Sweden (2001); Paris, France (2003); Nagasaki, Japan (2005); and Florence, Italy (2007).

In 1994 we had a ‘huge’ international attendance of nearly 300 physicians and one unforgettable patient, Suzanne Fleishman. Many of the 1994 attendees participated in their first international symposium and many of these ‘young physicians’ are now recognized as some of the key opinion leaders in MDS research and treatment. Their names are familiar to everyone working in the field of MDS and in 2009 they are familiar to many patients being treated for MDS worldwide: Ayalew Tefferi, Kazuma Ohyashiki, Irene Lorand-Metze, Luiz Fernando Lopes, David Bowen, Hugo Castro-Malaspina, Margaret O’Donnell, Carlos de Castro, Lyle Sensenbrenner, Peter Emanuel, Richard Stone, Gary Gilliland, Azra Raza, Denise Wells, Charlotte Niemeyer, Jaroslav Cermak, Detlef Haase, Steven Gore, Eva Hellström-Lindberg, Henrik Hasle, Elihu Estey, Richard Larson, Moshe Mittleman, Lewis Silverman, Christine Chomienne, Theofanis Economopoulos, Thornton Haferlach, Francois Dreyfus, Elizabeth Souto, Fernando Duarte, Philip Koeffler, Pierre Fenaux, Michelle Lebeau, Alan List, Guillermo Sanz, Masao Tomonaga, Cheryl Willman, Teresa Vallespi, and Ghulam Mufti.

Over these fast 15 years, growth of interest in MDS has evolved tremendously and we reached a pinnacle of attendance at the Florence symposium with over 1400 attendees. Attendance at the 10th International Symposium will rival that of Florence!

Suzanne Fleishman, the first MDS patient that I met face-to-face, left me with an indelible memory of her smiling face, her quest for knowledge about MDS after her diagnosis in 1993, and her sense of humor. Suzanne attended all of the International Symposia until her death in 2000. Her assessment of the physicians’ use of military language as a metaphor in medicine was unique and unforgettable. She wrote that people with illnesses are no longer the focus of medicine “but merely the clinical stage on which the main protagonists of the drama—the doctors and the disease—battle it out”. At the 10th International Symposium we will honor her memory with the Suzanne Fleishman Memorial Lecture, our practice since 2001, with a presentation by Dr. David Cella, “Symptom and Treatment Burden: Effect on Quality of Life”.

In 1994, the year the Foundation was established, we could offer MDS patients only the barest assurance that most people live a long time with this disease and the treatment of these syndromes was focused on supportive care alone. MDS patients were offered little hope of living out their normal life span.

By the late 1990s drug development and research began to rapidly evolve in MDS. In May of 2004 the first drug was approved
for the treatment of MDS, azacitidine (Vidaza), rapid succession came approval for lenalidomide (Revlimid) in December 2005 and decitabine (Dacogen) in May 2006. These drugs have significantly improved many patients’ quality of life and for the first time a drug, Vidaza, has shown in clinical trials that survival can be improved with therapy.

In the ‘blink of an eye’ we come together in Patras for this important symposium and MDS patients are inspired with hope for the future!

Results of a Pivotal Phase 3 Trial Are Published


In this pivotal phase III trial, intermediate-2/high-risk MDS patients (N=358) were randomized to receive azacitidine at 75 mg/m²/d sc × 7 days q28d cycle or conventional care (supportive care or low dose cytarabine or intensive chemotherapy). The primary endpoint was overall survival. Treatment cross-over and the use of erythropoiesis stimulating agents were not permitted. On treatment arm patients received a median of 9 cycles of azacitidine. After a median follow up of 21.1 months, the overall survival was superior for azacitidine (24.5 mo) as compared to those receiving conventional care (15 mo) with estimated 50.8% vs. 26.2% 2-year survival rates respectively. Patients with chromosome 7 abnormalities also demonstrated survival advantage with azacitidine.

Highlighted by Suneel Mundle, PhD.
The MDS Foundation Says Published Data Confirms Vidaza® Significantly Extends Survival in Patients With the Malignant Condition MDS

VIDAZA Restores Gene Function to Double Survival and Increase Transfusion Independence

Crosswicks, NJ (February 18, 2009) /PRNewswire/—The Myelodysplastic Syndromes (MDS) Foundation says data published in the peer reviewed medical journal The Lancet Oncology confirms VIDAZA extends survival for patients with higher-risk MDS. Myelodysplastic syndromes are a group of blood-related malignancies that are difficult to treat and in higher-risk patients have a median survival rate of less than one year. Symptoms include anemia and fatigue, and often patients must rely on blood transfusions to manage the symptoms. VIDAZA, also known by its chemical name, azacitidine, represents a new approach to treatment with important benefits for patients with MDS, and a related condition called acute myeloid leukemia (AML).

“The data from this large international study of VIDAZA is important news for the patients we represent, validating a new treatment option and offering tangible results for this difficult-to-treat disease,” said Kathy Heptinstall, Operating Director of the Myelodysplastic Syndromes Foundation.

“VIDAZA was able to essentially double survival at two years compared to conventional care,” says Lewis Silverman, M.D., of Mount Sinai Medical Center in New York and senior study author. “VIDAZA is the first and only drug that we know extends survival.”

In MDS, genes responsible for orderly growth and development of cells in the bone marrow are turned off or silenced, allowing the cells to become malignant. VIDAZA turns these genes back on through a system of actions called epigenetics, a new approach to cancer treatment. It is also the first drug to achieve transfusion independence in more than 40% of patients. Transfusions can be time consuming, debilitiating and run the risk of iron overload that can be fatal.

MDS patient Bob Urbanski notes, “I needed blood transfusions as often as twice a month, but with VIDAZA I haven’t needed a transfusion for at least 14 weeks.”

The published data refer specifically to categories of MDS known as intermediate-2 or high-risk MDS, as well as AML with 20 to 30 percent bone marrow blasts. VIDAZA has been available in the United States for four years and it was recently approved in Europe.

Data Presented at ASH Illustrates That Continued Treatment With Vidaza Can Benefit MDS Patients

Crosswicks, NJ (December 8, 2008)—The Myelodysplastic Syndromes (MDS) Foundation announced today that a new analysis of the AZA-001 phase III clinical trial demonstrates that continued treatment with VIDAZA (azacitidine) can improve response rates for higher-risk MDS patients.

Leading hematologist Dr. Lewis Silverman of Mount Sinai Medical Center presented the analysis at the 50th Annual Meeting of the American Society of Hematology. The results showed that 51% of patients in the trial responded to treatment with Vidaza. Of those patients, almost half achieved an improved response when treatment with VIDAZA was continued for an additional four cycles.

“We are encouraged by this analysis which for the first time shows that patients can benefit from continued treatment with VIDAZA,” said Kathy Heptinstall, Operating Director of the Myelodysplastic Syndromes Foundation, “This analysis provides hope for many MDS patients that do not initially have a strong response to treatment. We look forward to additional studies that showcase the clinical potential of epigenetic therapies like VIDAZA.”

Dr. Silverman’s analysis is a follow-up to results from the AZA-001 trial, presented at the American Society of Clinical Oncology meeting in June, which showed that VIDAZA significantly extends overall survival for patients with MDS compared to conventional care regimens (CCR). Patients who received VIDAZA had higher one-year survival rates in all response categories, including partial remission, stable disease and hematologic improvement, compared to those who received CCR without necessarily achieving complete remission.

MDS is a primary neoplasm of the bone marrow that is more prevalent than any of the leukemias. MDS affects the function of blood cells, either red blood cells, white blood cells or platelets. The incidence of MDS is underestimated.
Dacogen® (decitabine for injection) Data Presented on a Phase II Clinical Trial in Elderly Patients with Acute Myeloid Leukemia (AML)

Response Observed Across All Subtypes of AML, Including Those with Poorest Prognoses

On December 8, 2008, Eisai Corporation of North America announced at the American Society of Hematology (ASH) 50th Annual Meeting, data from a Phase II trial evaluating a five-day dosing regimen of Dacogen® (decitabine for injection) in acute myeloid leukemia (AML), the most common form of leukemia. The trial involved elderly patients with AML, who often have limited options due to comorbidities and are typically considered ineligible for standard induction chemotherapy.

Dacogen® is currently indicated for the treatment of patients with myelodysplastic syndromes (MDS), including those with refractory anemia with excess blasts (immature or unformed blood cells) in transformation (RAEB-T — now re-classified by World Health Organization [WHO] as AML). Phase II and III clinical trials evaluating Dacogen® in patients with AML are currently underway.

The primary objective of this multicenter, open-label, Phase II trial was to establish the morphologic complete response (CR) rate. Dacogen® was administered intravenously over one hour for five consecutive days every four weeks at a dose of 20 mg/m² and 100,000/uL, respectively. The majority of patients in the trial had intermediate or poor risk cytogenetics (bone marrow tests to identify abnormal chromosomes). Responses were observed across all patients including those with poor risk cytogenetics, those whose AML transformed from MDS, or those who developed AML after previous treatment for cancer.

The five-day dosing regimen of Dacogen® is currently being further evaluated in a global, Phase III survival study in elderly patients with AML.

PRESS RELEASE FROM NOVARTIS

Exjade® Benefits Chronically Transfused Patients By Significantly Reducing Toxic Iron That Can Damage Key Organs, According To Landmark Trial

On December 9, 2008, Novartis Pharmaceuticals Corp. announced new data from the largest prospective trial in iron chelation demonstrated the efficacy and safety of Exjade® (deferasirox) in treating chronic transfusional iron overload, a potentially life-threatening condition for patients who have had multiple blood transfusions to treat underlying anemias, including beta-thalassemia and myelodysplastic syndromes (MDS).

Data from this trial, known as EPIC, were presented at the 50th American Society of Hematology (ASH) Annual Meeting in San Francisco, California. The EPIC trial was a one-year, open-label, prospective, multicenter trial. EPIC studied the efficacy and safety of a fixed starting dose of Exjade based on transfusional iron intake, with subsequent dose titration at 3-monthly intervals based on serum ferritin (SF) trends. The trial included 1,744 patients including patients with beta-thalassemia, MDS and aplastic anemia.

The EPIC cardiac substudy evaluated the cardiac efficacy of Exjade in 114 beta-thalassemia patients with myocardial siderosis (T2* <20 ms). The substudy showed that Exjade removed iron from the heart in beta-thalassemia patients, based on a statistically significant improvement in T2* magnetic resonance imaging, a validated technique to assess cardiac iron content (P<0.0001). The one-year substudy included 114 beta-thalassemia patients with cardiac iron overload, the leading cause of death in these patients. The data showed that deferasirox significantly reduced cardiac iron in these patients. There is an ongoing one-year extension of this substudy.

A pre-planned subgroup analysis of the EPIC study included 341 patients with transfusion-dependent MDS and SF levels ≥1000 ng/mL, or SF <1000 ng/mL, but with a history of multiple transfusions (>20 transfusions or 100 mL/kg of red blood cells) and an R2 MRI-confirmed LIC >2 mg Fe/g dw. The pre-planned analysis of the 341 MDS patients enrolled in the study showed that Exjade significantly reduced levels of serum ferritin (SF), a key measure of iron in the body, by 253.0 ng/mL from baseline (P=0.0019). Of the 171 MDS patients whose SF was measured at one year, the decrease from baseline was 606 ng/mL.

Many MDS patients receive regular blood transfusions as part of their ongoing treatment, which puts them at risk for iron overload. This study shows deferasirox can effectively reduce iron burden and is generally well tolerated when used appropriately to treat these patients.

Iron toxicity can lead to permanent damage of the liver, heart and endocrine glands, leading to an increased risk of serious health problems and early death. Previous studies of transfusion-dependent MDS patients have found that increased levels of SF are associated with shortened overall survival.

Exjade is indicated for the treatment of chronic iron overload due to blood transfusions (transfusional haemosiderosis) in adult and pediatric patients (aged 2 years and over). The approved indication may vary depending upon the individual country.
Meeting Highlights and Announcements

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

AMERICAN SOCIETY OF HEMATOLOGY

Integrating New Developments in MDS into Clinical Practice

Moscone Center South
San Francisco, California
December 4, 2008

The MDS Foundation held its 11th consecutive satellite symposium on Friday preceding the American Society of Hematology’s annual meeting. This symposium entitled “Integrating New Developments in MDS into Clinical Practice,” was chaired by Dr. John M. Bennett of the University of Rochester Medical Center in New York State and Chairman of the MDS Foundation and its Board of Directors. More than 1500 people attended this symposium.

This symposium was designed to comprehensively integrate and evaluate new information in MDS research, diagnosis, stratification, biology, treatment and “tracking” of MDS patients. A thorough overview of the upsurge in unique therapies under investigation were presented; cutting-edge information on the role of immunopathology in MDS was explored; improvements in the morphologic classification and diagnosis of MDS was explained; innovative new research designed to broaden knowledge and improve techniques in testing for and analysis of MDS cytogenetics were presented by the International Working Group on MDS Cytogenetics; the evolution of the prognostic scoring systems for MDS (IPSS and WPSS) aimed at improving patient stratification was presented; a new state-of-the-art methodology to “track” MDS patients that was designed to provide real-time alerts to the clinician regarding disease progression and/or response to MDS therapy; and, finally, an exploration of the path(s) that will make combination therapy a reality for MDS patients.

The topics and international faculty for this symposium included:

- What and “WHO” Is New in MDS?
  John M. Bennett, MD, Chairman
  University of Rochester,
  James P. Wilmot Cancer Center
  Rochester, New York

- Understanding the Immunopathogenesis in MDS
  P.K. Epling-Burnette, PhD
  H. Lee Moffitt Cancer Center and Research Institute
  Tampa, Florida

- Making Combination Therapy a Reality
  Guillermo Garcia-Manero, MD
  MD Anderson Cancer Center
  Houston, Texas

- Adapting the Role of Prognostic Scoring in the Treatment of MDS
  Detlef Haase, MD, PhD
  University of Göttingen
  Göttingen, Germany

- Understanding the “Novel” in MDS Therapy
  Alan F. List, MD
  H. Lee Moffitt Cancer Center and Research Institute
  Tampa, Florida

- Changing the Landscape of Cytogenetics
  Marilyn L. Slovak, PhD
  City of Hope
  Duarte, California

If you would like a copy of the CD ROM containing the video and slide presentations from this symposium you can contact The MDS Foundation, 36 Front Street, P.O. Box 353, Crosswicks, NJ 08515, Tel. 1-800-MDS-0839 or visit our website www.mds-foundation.org.

REPRINTED FROM ASH NEWS DAILY

The Myelodysplastic Syndromes Breakfast Club

David P. Steensma, MD

One of the most remarkable stories surrounding the ASH annual meeting in recent years has been the dramatic growth of interest in the myelodysplastic syndromes (MDS). In the 1990s, MDS-related programs were held in small rooms in difficult-to-find corners of convention centers, and there were usually at least a few empty chairs. But better understanding of disease biology, and especially increased availability of efficacious treatments, has changed all that.

At last year’s meeting in Atlanta, more than 3,000 people attended the MDS education session, the MDS-related scientific sessions were standing-room only, and an exciting MDS-related observation about ribosomal protein S14 was featured in the Plenary Scientific Session. This year’s MDS education sessions—despite their 7:30 a.m. start time today and Sunday—will also draw large (and presumably heavily caffeinated) crowds, so they will be held in Halls B and C of the Moscone Center.

In the May 15, 2008, issue of Blood, as part of series of review articles celebrating the 50th anniversary of ASH, Dr. Stephen Nimer,
of Memorial-Sloan Kettering Cancer Center, prepared a valuable and provocative summary of the current state of the MDS field. At the MDS education sessions today and tomorrow, Dr. Nimer will focus on the stem cell abnormalities that may contribute to the development of MDS, especially lower-risk forms of MDS where the stem cell defect is more difficult to understand, such as the peculiar 5q- syndrome that has generated so much recent interest. Although Dr. Nimer points out that immunological abnormalities and defects in the bone marrow microenvironment are also likely to be important in MDS pathobiology, his presentation will reflect the fact that most research work has focused on the hematopoietic stem cell/progenitor cell compartment.

The session will be chaired by Dr. Eva Hellström-Lindberg, from the Karolinska Institutet in Stockholm, who recently served as president of the European Hematology Association (EHA). Dr. Hellström-Lindberg will discuss the significance of the JAK2 V617F kinase activating mutation for MDS. The discovery of JAK2 V617F in 2005 was an important advance in myeloid disease biology and in the clinical care of patients with myeloproliferative neoplasms (MPNs), but JAK2 is also relevant to MDS—especially in patients with features of both MDS and MPNs, such as those with both ring sideroblasts and thrombocytosis. Dr. Hellström-Lindberg has a long-standing interest in refractory anemia with ring sideroblasts (RARS), and her laboratory group has published key observations concerning mitochondria-mediated apoptosis and accumulation of mitochondrial ferritin in erythroid precursor cells with MDS, upon which she will elaborate.

Although the roster of non-transplant therapeutic options for patients with MDS is growing, rather risky allogeneic stem cell transplantation (SCT) remains the only routinely curative treatment. Transplant expert Dr. Nicolaus Kröger, of University Hospital Hamburg-Eppendorf in Hamburg, will review evolving approaches to SCT in MDS, including updates of reduced-intensity conditioning regimens and a discussion of ways to approach patients relapsing after SCT. Professor Kröger will also discuss possible roles for DNA methyltransferase inhibitors azacitidine and decitabine in SCT, including how these drugs might be used to prepare patients for SCT—or maintain remission achieved by SCT, since relapse is so common.

Since all three of these presenters hail from at least three time zones to the east of San Francisco, they should already be wide awake at 7:30 a.m., leading to a dynamic session. For those of us in the audience who might not be quite as energetic that early, this lineup is well worth setting the alarm clock for.

10th International Symposium on MDS
May 6-9, 2009 • Patras, Greece

Message from the Organizers
Dear Colleagues,
We have the great pleasure to welcome you to the 10th International Symposium on Myelodysplastic Syndromes, which is being held in Patras, Greece, from May 6–9, 2009.
The important progress in the pathogenesis and treatment of the Myelodysplastic Syndromes gave the Scientific Committee the opportunity to create a very interesting Scientific Program with speakers who are leaders in the field, while expanding also the opportunity for oral and poster presentations. We are also for the first time organizing a Young Investigator’s Plenary Session, where the Bastianello Awards will be presented to the selected speakers.
The Patras meeting is also hosting a Nursing Education Program, a Patient and Family Forum, an Interactive Morphology Workshop, a Challenge the Experts Session, and a Poster Walk, with the hope to provide incentives to attendees working in basic and clinical research as well as those caring for our patients, for increased participation and provision of critical information in unique formats.
Patras is a significant university city in proximity to both Olympia and Delphi, an ideal spot for attendees who would like to combine their scientific interests with the opportunity to visit these beautiful and historic sites and to visit a beautiful landscape especially in the month of May.
The Symposium will also provide continuing education credits within the European Hematology Association CME program.
Thank you very much for joining us in Patras and we wish success in your scientific goals and a pleasant stay.
Nicholas C. Zoumbos, MD
Chairman, 10th Int’l Congress on MDS
John M. Bennett, MD
Chairman, MDS Foundation

Scientific Program
WEDNESDAY, MAY 6, 2009
Suzanne Fleischman Memorial Lecture
Symptom and Treatment Burden: Effect on Quality of Life
David Cella

THURSDAY, MAY 7, 2009
Pathogenesis I: Immunopathogenesis in MDS
Ghulam J. Mutti, Chairman
MDS. An Immune Disorder?
Ghulam J. Mutti
Diagnosis of Immune Pathophysiology in Patients with Low-risk MDS
Shinji Nakao
Controlling the “Fate” of T-cells in MDS
P.K. Epling-Burnette
Telomere Biology and the Pathogenesis of Clonal Evolution from Bone Marrow Failure
Neal Young

Pathogenesis II:
Molecular Pathogenesis in MDS
Neal Young, Chairman
BMI-1 and AML-1 Point Mutation in the Pathogenesis of MDS
Akiro Kimura
Molecular Changes as Detected by High-throughput Genomic Techniques in MDS
Wolf-Karsten Hofmann
Gene Expression Profiling in Patients with MDS (Including Patients with the Del [5q])
Jacqueline Boulwdoo
Clinical and Pathogenetic Implications of Array-based Karyotyping in MDS
Jarosław P. Maciejewski

A DVD-ROM containing selected presentations from this symposium will be available upon request from the MDS Foundation.
Diagnosis and Prognosis I
Peter L. Greenberg, Chairman
MDS: Update on Classification
John M. Bennett
Real-time Prognostic Evaluation in MDS
Luca Malcovati
Updated Cytogenetic Risk Features in MDS — Present State
Detlef Haase
Update of Cytogenetic Risk Factors in MDS (Part II): A Strategy to Incorporate Fluorescence in situ Hybridization (FISH) and “FISH on a Chip” (aCGH) Results in Future Clinical Trials for the MDS
Marilyn L. Slovak

Morphology Workshop
John M. Bennett, Jean Goasguen
The interactive morphology workshop will be conducted during lunch and will be open to the first 300 in a separate luncheon session.

Diagnosis and Prognosis II
Denise Wells, Chairman
Disruption of Precise Gene Product Expression in Myelodysplasia
Michael R. Loken
Identification of Prognostic Subgroups by Flow Cytometry in MDS
Arjan A. van de Loosdrecht
Immunophenotypic Abnormalities Allow Distinction Between Normal/Reactive and MDS Bone Marrow: How to Make it Easier?
Alberto Orfao

Challenging the Experts: Case Studies
Moshe Mittelman, Constantinos Tsatalas
Co-Chairs

Simultaneous Sessions
Session I: Diagnosis and Prognosis
Guillermo Sanz, Michael Voulgarelis, Co-Chairs

Session II: Molecular Mechanisms and Pathophysiology
Jens Pedersen Bjergaard, Constantina Sambani, Co-Chairs

Nursing Education Program – Session I:
Understanding MDS: Disease Overview
Erin P. Demakos, Phyllis Paterson, Co-Chairs

FRIDAY, MAY 8, 2009
Overlap and Borderline States
Mario Cazzola, Chairman
MDS with Unilineage Cytopenia (Neutropenia/Thrombocytopenia)
Helen Papadaki
MDS with Marrow Fibrosis
Matteo Giovanni Della Porta
Chronic Myelomonocytic Leukemia
David T. Bowen
Refractory Anemia with Ringed Sideroblasts Associated with Marked Thrombocytosis
Mario Cazzola
Juvenile Myelomonocytic Leukemia
Christian Flotho

Patient and Family Forum
Argiris Symeonidis, Kathy Hepinstall, Co-Chairs
Low-grade MDS & Marrow Failure States
Charlotte M. Niemeyer, Chairman
Refractory Cytopenia of Childhood: Separating AA and Inherited Bone Marrow Failure Disorders – Results of Therapy
Charlotte M. Niemeyer
Inherited Syndromes and Low-risk MDS: Lessons Learned from the Greek Pediatric MDS Registry
Sophia Polychronopoulou
PNH: New Options
Anita Hill

Chelation Therapy: Issues & Answers
Alexandra Kourakis-Symeonidis, Chairman
The Basics: Iron Overload
Chaim Hershko
Prospective Studies in Chelation Therapy
Christian Rose
Assessing the Guidelines on Iron Chelation in MDS – Where are We?
Norbert Gattermann
Iron Toxicity & Chelation Therapy in Allogeneic SCT
Theo J.M. de Witte

Optimizing Epigenetic Therapies
Issues and Strategies
Michael Lübbert, Chairman
In Vitro Basis for Treatment with Hypomethylating Agents and HDAC Inhibitors: Can Epigenetic Changes by Used to Monitor Treatment?
Steven D. Gore
Review of Trials with Azacytidine in Higher-risk MDS
Pierre Fenaux
Decitabine in the Treatment of Higher-risk MDS
David Steensma
Hypomethylating Agents in MDS Changing the Inevitable: The Value of Maintenance Therapy, Effects on Transfusions and Combination with Other Agents
Lewis Silverman
Hypomethylating Agents in Lower-risk MDS
Valeria Santini

New Agents in MDS
Pierre Fenaux, Chairman
Should We Use Histone Deacetylase Inhibitors in the Treatment of MDS?
Allen S. Yang
Thrombopoietic Growth Factors
Mikkael Sekeres

Lecture: Innovative Clinical Trial Design in MDS
Elihu Estey

Simultaneous Sessions
Session III: Molecular Mechanisms and Drug Targets
Theofanis Economopoulos, Photis Beris, Co-Chairs

Session IV: Therapy & Experimental Models
Valeria Santini, Nikolaos Harhalakis, Co-Chairs

Nursing Education Program – Session II:
Case Presentations: Managing MDS Patients Effectively
Erin P. Demakos, Phyllis Paterson, Co-Chairs

SATURDAY, MAY 9, 2009
Risk-adapted Treatment Strategies and Novel Therapies
Alan F. List, Chairman
Low-risk MDS: Transfusion Therapy, Growth Factors and the European View on Lenalidomide
Eva Hellström-Lindberg
Management of del (5q) MDS
Aristoteles Giagounidis
Developmental Therapeutics for MDS
Alan List

Evolution in Transplantation in MDS
Theo de Witte, Chairman
Allogeneic Stem Cell Transplantation in MDS: Reduced Intensity Conditioning and Donor Lymphocyte Infusion
Nicolaus Kröger
New Preparatory Regimens: The Role of New Drugs
Michael Lübbert
Reducing the Frequency of Relapse After Hematopoietic Cell Transplantation for MDS
Joachim Deeg
Reduced Intensity Regimens in Refractory Cytopenia
Marco Zecca

Young Investigator’s Plenary Session and Tito Bastianello Awards
Nicholas Zoumbos, David Bowen, Co-Chairs

Closing Remarks and Announcement of the 11th International Symposium on MDS
Nicholas Zoumbos, John Bennett, David Bowen
PLEASE PLAN TO ATTEND!

Agenda
8.00—8.05  Welcome and Introduction
            David T. Bowen, MD, Chairman
8.05—8.25  Treating Low-risk MDS: Evidence-based Therapy
            Moshe Mittelman, MD
8.25—9.05  RARS-t: Issues in Management and Treatment
            Mario Cazzola, MD
8.45—9.05  Innovative Management of INT-1
            David T. Bowen, MD
9.05—9.25  Effective Therapeutic Choice in High-risk MDS
            Pierre Fenaux, MD
9.25—9.45  The Role of Induction Chemotherapy in High-risk MDS
            Theo J.M. de Witte, MD, PhD
9.45—10.00 Reframing Treatment Schema
            David T. Bowen, MD

Program Overview
This program will provide participants with the opportunity to match their knowledge of MDS with that of a panel of experts in MDS diagnosis and therapy. Accurate diagnosis, stratification of MDS patients, treatment choices, and assessment of outcomes (including quality of life issues) provides everyone involved in treating MDS, including this ‘Expert Panel’, with continuous challenges to optimization of outcomes for MDS patients. The Expert Panel will present brief overviews of only the most recent treatment advances and proceed to a series of ‘real life’ cases. Verbal interaction and electronic decision making will allow for full participation by the audience and provide them with the opportunity for challenging face-to-face discussions with the experts and other participants.

Faculty
David T. Bowen, MD  Chairman
Consultant Haematologist
St. James’s Institute of Oncology
Leeds, United Kingdom

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

Theo J.M. de Witte, MD, PhD
Professor of Hematology
University Medical Center
Nijmegen St. Radboud
Nijmegen, The Netherlands

Pierre Fenaux
Professor of Hematology
Hôpital Avicenne
University Paris 13
Bobigny, France

Moshe Mittelman, MD
Director, Department of Medicine
Tel-Aviv Sourasky Medical Center
Tel-Aviv, Israel

Foundation Plans International Symposia Through 2013

The MDS Foundation has approved applications for the next two International Symposia. These symposia are scheduled for 2011 in Edinburgh, Scotland, and 2013 in Berlin, Germany.

Eleventh International Symposium:
   Spring 2011
Edinburgh, Scotland
Sponsor: David T. Bowen, MD

Twelfth International Symposium:
   Spring 2013
Berlin, Germany
Sponsor: Wolf-Karsten Hofmann, MD, PhD
Air Transportation Options for Patients

Air transportation resources may be available for patients considering travel to one of the participating sites that are part of the NIH Rare Diseases Clinical Research Network (RDCRN).

Angel Flight’s volunteer pilots provide flights in single-engine, four-six seat general aviation aircraft to patients at no charge. To be eligible, patients must be medically stable, ambulatory, and able to sit upright in an aircraft seat during flight. Angel Flights are for patients in financial need and who have their medical status certified by their doctors. An escort may accompany the patient, and children may be accompanied by both parents.

Flight distances are limited to 1,000 miles. Weight restrictions apply and luggage is limited to 50 pounds. Safety is a primary concern. Pilots will not fly in poor weather. Patients need to be flexible, have a back up plan or be willing to reschedule their appointments.

If you are interested in finding out if Angel Flight meets your air transportation needs to participate in a clinical research study, contact Marita Eddy at 301-451-9646 or meddy@mail.nih.gov.

For patients who live farther than 1,000 miles, other resources may be available through Mercy Medical Airlift.

Mercy Medical Airlift (MMA), a non-profit organization celebrating 25 years of medical air transportation experience, manages programs and services available to patients with both common and rare diseases.

If you are flying to any of the RDCRN facilities or going to a study at the NIH Clinical Center in Bethesda, Maryland, contact Marita.

For patients who are looking for travel help to other locations, call the National Patient Travel Center at 800-296-1217 or check www.patienttravel.org.

UNIVERSITY AIRLINES CHARITY MILES

☐ I want to help Mercy Medical Airlift provide free air transportation to patients in financial need.

Please process a gift of ___________ Dividend Miles from my United Airlines account. (Please fill in number of miles – donations must be in 1,000 mile increments)

Name: _______________________________________________________________________________

Print Full Name

Email Address: _________________________________________________________________________

United Mileage Plus Account Number: ____________________________________________________

United.Com Password: _________________________________________________________________

Phone Number: _______________________________________________________________________

Address: ______________________________________________________________________________

City: __________________________ State: _______ Zip Code: __________

Signature: __________________________ Date: ______________

Remarks: ____________________________________________________________________________

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_____________________________________________________________________________________

Please mail to:
Marita Eddy, Angel Flight-MMA
NIH Office of Rare Diseases Research
6100 Executive Blvd. MSC 7518
Bethesda, Maryland 20892

25,000 Frequent Flyer Miles equals 1 round-trip ticket
Patient Forums and Support Groups

Patient Support Group Initiative

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

Would you be interested in joining with a few other people to help start a needed support group for MDS? Monetary assistance is now available to help you develop a self-help group. The purpose of this group is to exchange information and resources, to provide comfort and support to patients and caregivers, and to explore the challenges of living with myelodysplastic syndromes.

Studies and other literature show that patients facing chronic or terminal illnesses, as well as their families and friends, benefit in numerous ways from participating in patient support groups. These groups not only provide a source for obtaining current information on the disease, treatment options and research, they also offer a supportive environment in which to express fears and concerns and share experiences with others coping with similar conditions. In fact, patients who participate regularly in support groups report reductions in stress, depression, and even pain.

Any member of the Foundation, patients, friends, family members, and caregivers are invited to join with us to move this project forward.

Raising The Next Generation of MDS Investigators

MDS is an enigmatic disease that is not yet well understood by scientists, physicians, and researchers. It is essential to develop the new generation of researchers so that the causes of these syndromes are identified as soon as possible. To ensure that this future generation of researchers flourishes, the MDS Foundation will award two (2) fellowships of $50,000 each in 2009.

The Foundation is dedicated to furthering the research into MDS and invites young investigators (under 40 years of age) from institutions that form our MDS Centers of Excellence to submit their proposals.

This year the deadline for the Letter of Intent will be June 15th, with formal applications due by August 17, 2009. Notification of the awards will occur by October 1, 2009 with activation on January 1, 2010.

The two Young Investigator Grants awarded for 2010 will be announced on December 4, 2009 at a formal awards ceremony to be held in conjunction with the American Society of Hematology’s annual meeting in New Orleans, Louisiana.

International and Country Congresses and Emerging MDS Societies

International Congresses

We are continuing to participate in countrywide as well as EU-wide meetings that we have previously attended and striving to expand into other major European countries and actively participate in their society meetings.

- American Psychosocial Oncology Society
- Oncology Nursing Society
- American Society of Clinical Oncology
- BIO International Convention
- International Society of Experimental Hematology
- American Society of Hematology
- European Group for Blood and Marrow Transplantation
- British Society for Hematology
- European Hematology Association
- International Society of Hematology
- Groupe Français des Myélodysplasies
- Czech & Slovak Congress in Hematology
- Romanian Society of Hematology
- Society of Portuguese Hematology

MDS Foundation Patient Liaisons

PLEASE CONTACT:

US Patient Liaison
Audrey Hassan
ahassan@mds-foundation.org
P.O. Box 353
Crosswicks, NJ 08515
Tel: 1-800-MDS-0839
Outside the US only
609-298-6746
Fax: 609-298-0590

EU Patient Liaison
Sophie Wintrich
Swintrich@mds-foundation.org
The Rayne Institute, Denmark Hill Campus
123 Coldharbour Lane
London SE5 9NU, UK
Tel: +44 20 7733 7558
Highlights From Around the World...

Columbia, South Carolina
March 7, 2009

Kathy Heptinstall, Operating Director, MDS Foundation speaking with attendees


Physician Forum chaired by Gary Spitzer, MD, Greenville, SC.

Nursing Symposium Program provided new information regarding quality-of-life in MDS patients, nursing and patient resources, new definitions and research in morphology and cytogenetics that are important in the evolution of the prognostic scoring systems (IPSS and WPSS), treatment strategies and drug therapy, as well as the first look at a unique tool for online tracking of MDS patients.

European MDS Patient and Family Forum
Frankfurt, Germany, March 6-7, 2009

Kathy Heptinstall, Operating Director, MDS Foundation speaking with attendees

Patients and their guests in Frankfurt, Germany

Dr. Gary Spitzer from the Cancer Center of the Carolinas was the guest speaker at the MDS Patient-Caregiver Forum.
Second Latin American Symposium on MDS
Buenos Aires, Argentina, November 20–21, 2008

Kathy Heptinstall and Dr. John Bennett with two of the meeting organizers.

European MDS Patient and Family Forum: Patient Feedback
Linda Sheppard
March 6–7, 2009
Frankfurt, Germany

My name is Linda Sheppard and I live in East Sussex, England. I am aged 54 and was diagnosed with Myelodysplastic Syndromes — Acute Red Cell Aplasia in December 2006. My blood count was 3.9, I was acutely anaemic and immediately admitted to the hospital requiring 6 blood transfusions to stabilize me. In laypersons terms, this meant that I had no red blood cells in my body at all, resulting in my white blood cells unhealthily overcompensating for the missing red cells. I was kept alive by regular blood transfusions until I received a bone marrow transplant at Kings College, London in January 2008. I often wondered what it would be like to have curly hair — as I have always had very thick straight hair — and after receiving my pre-BMT conditioning chemo my hair fell out and has since grown back curly!

I am a member of the UK MDS Patient Support Group committee and attended the European MDS Patient & Family Forum held on the March 6–7, 2009, at the Hilton Hotel, Frankfurt City, Germany.

Leading up to the Forum date, I really did not know if I would have the energy levels or feel well enough on the day to attend. But I took a chance and booked the flight to go. I am really pleased that I did make the effort, as the European Forum proved to be very informative, helpful, and reassuring. The haematology medical experts and MDS Foundation representatives that attended are dedicated and passionate about the care available to their patients and take MDS very seriously. They are constantly working to improve methods of treatment, share knowledge, and raise the profile of this (little known and hard to diagnose) disease.

The format of the two days consisted of 3 main speakers:

Drs. David Bowen, MD; Leeds Teaching Hospital, UK; Wolf-Karsten Hofmann, MD, PhD; University Hospital Mannheim, Germany; and Valeria Santini, MD; University of Florence, Italy.

Janet Hayden—Myeloid Clinical Nurse Specialist from Kings College Hospital, London, and Claudia Boglione—MDS specialist nurse from Florence, Italy, were also on hand to share information and to answer patient questions.

John Farquhar Munro (Member of Scottish Parliament) is an MDS patient who was a guest speaker and talked about his journey with his illness.

Chairing and answering questions at the event was Kathy Heptinstall, Operating Director, MDS Foundation Inc, Crosswicks, New Jersey, USA.

There were approximately 30 attendees — half of which were patients, caregivers, and family members representing Germany, Britain, Switzerland, Czech Republic, Greece and France.

Dr. Bowen (UK) gave a very thorough and interesting brief on the wide variation of blood diseases that MDS covers. It is a very rare disease—approximately 4–5 new cases are diagnosed per 100,000 population per year. 7,000 to 9,000 patients live with MDS within the UK at any one time (which is a small amount compared with other types of cancer). There are probably a lot more people with the illness that go undetected, as the symptoms can mimic other illnesses and general physicians (GPs) can miss the signs. There is currently no way to gauge as to how and when the MDS disease develops within the body—a Glasgow study shows that the illness can start as early as 6 years prior to diagnosis. In the vast majority of patients the cause is unknown. To date there is no evidence as to what triggers or causes MDS. There is no research or evidence to link passing on MDS genetically/family to family. Patients fitness/age has an impact on the treatment available. MDS tends to get more common as people get to their older years (stats taken from Dusseldorf paper show increase in 74–75 years and up).
Professor Valerie Santini (Italy) talked about “Quality of Life” being well, being happy. She described “Health” as a complete physical, mental and social well being. Quality of life differs from country to country. Every culture has a different context on what is quality of life. Points to consider are: Physical Health (energy/fatigue); Psychological State (body image, negative/positive feelings, self esteem); and Environmental (financial resources, freedom, physical safety, recreation). What is affecting the quality of life of the patient? Things to consider: Hospital dependence/control? Fatigue/transfusions? Infections/antibiotics/drugs? Mental well-being? Domestic/family issues?

Professor Dr. Wolf-Karsten Hofmann (Germany) talked about blood transfusions and iron overload— the cause, potential side effects and remedies, and explained the option of a bone marrow transplant (BMT) — the survival rate is 30%–40%. The first couple of years post-BMT are crucial for the patient to get through. Graft vs host disease can be a common side effect of BMT and may present in different forms. Long-term (anti-rejection) transplant drugs are usually prescribed to BMT patients. All doctors gave presentations on technical data pertaining to MDS and talked about the way forward with stem cell treatment and a new series of drugs.

In summary, the points that became clear to me were: a) Approaches to an individual patient’s treatment vary from county to county within Britain (postcode lottery?). There appears to be an unfair balance as to whether patients can gain access to certain drugs that may benefit their illness. MDS profiles need to be raised with our GPs as there is still a lack of understanding in diagnosing the illness. b) Not all patients appear to have access to the full range of diagnostic tests; c) Patients in some EU countries have less support, access to knowledge, and resources available (blood transfusions/certain drugs/lack of funding).

In UK there is a nationwide organized network of hospitals that work together— made up of haematology-specialist nurses and doctors. This is not happening in other parts of EU.

What can we, the patients/care-givers/family, do? We can carry on networking with each other, and sharing responsible and reliable information— which in turn will help to empower you to make the best informed decision for your specific illness.

Please try and find the best expert consultant for your particular illness. If you do not feel confident in the information or treatment you have received to date, then you have the option to seek a second opinion or alternatively check out the information provided by the websites:

www.mdspatientsupport.org.uk

Whenever possible, we need to lobby and campaign our government to improve treatment in every field of MDS.

With my own journey: at the time of receiving treatment I did not feel the need to read other peoples blogs and research my illness. Once I knew what the prognosis was, the consultants kept me fully informed. I had every confidence and felt ‘safe’ with the ongoing treatment and care I received from both my local Haematology Unit at Eastbourne Hospital, and Kings College Hospital, London (where my bone marrow transplant took place). Whilst I put my trust in the consultant doctors, I still asked questions on anything I did not understand or agree with.

Everyone of us is different as is our illnesses. There is no right or wrong way to deal with your illness — whatever is best for you as an individual is the right way to go.

Every day for me is a “good day” whether I am feeling well or confined to my bed.

As for my family, I have three sons aged 25, 21 and 15. I have chosen to keep them informed throughout my illness and whilst I have made a good recovery so far, I know I still have a way to go, and so I share this with my sons. As quoted by the doctors “Enjoy when you can, endure when you must”.

MDS Practice and Treatment Survey

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

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

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

The results of this expanded survey will be shared with each of our Centers of Excellence and used by the Foundation to assess new educational and research opportunities. Please assist us by completing a brief online survey. Go to www.mds-foundation.org and click on the Physician or Nursing Practice & Treatment Survey.

Surveys are available online in the following languages: Spanish, Italian, German, and Dutch.

Thank you in advance for your consideration in completing this form.
Spreading the Word Worldwide – Quality-of-Life and Patient Education Forums

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

UNITED STATES
- New York City, New York (October 2004, December 2006)
- Tampa, Florida (November 2004)
- Palo Alto, California (December 2004)
- Scottsdale, Arizona (February 2005)
- Chicago, Illinois (March 2005)
- Pittsburgh, Pennsylvania (February 2006)
- Oak Brook, Illinois (January 2007)
- Dallas, Texas (January 2007)
- Seattle, Washington (March 2007)
- Covina, California (March 2007)
- Rochester, Minnesota (June 2007)
- Baltimore, Maryland (September 2007)
- Philadelphia, Pennsylvania (February 2008)
- Rochester, New York (April 2008)
- Los Angeles, California (May 2008)
- Scottsdale, Arizona (May 2008)
- San Antonio, Texas (August 2008)
- Atlanta, Georgia (November 2008)
- Columbia, South Carolina (March 2009)

EUROPE
- Edinburgh, Scotland UK (March 2005)
- Paris, France (January 2006)
- Bournemouth, England UK (February 2006)
- London, England UK (February 2006)
- Hamburg, Germany (April 2006)
- Marseille, France (May 2006)
- Vienna, Austria (July 2006)
- Prague, Czech Republic (September 2006)
- Stockholm, Sweden (September 2006)
- Freiburg, Germany (February 2007)
- London, United Kingdom (May 2007)
- Florence, Italy (May 2007)
- Dubrovnik, Croatia (September 2007)
- Sinaia, Romania (October 2007)
- Toulouse, France (May 2008)
- Copenhagen, Denmark (June 2008)
- Lund, Sweden (September 2008)
- Buenos Aires, Argentina (November 2008)
- Tel Aviv, Israel (January 2009)
- Frankfurt, Germany (March 2009)
- Stockholm, Sweden (April 2009)
- Patras, Greece (May 2009)

EU PATIENT AND FAMILY FORUM
Frankfurt, Germany (October 2008, March 2009)

The 2008 Forum assembled 40 patients from across Europe for a Patient and Family Forum that provided interactive and didactic updates from key clinicians and nurses.

The second meeting was held March 5-7, 2009 in Frankfurt with 48 attendees from the United Kingdom, Czech Republic, France and Germany.

Forums to be held in 2009:
- Baltimore, Maryland: June 13
- Tucson, Arizona: June 27
- Chicago, Illinois: July 11
- Philadelphia, Pennsylvania: July 15
- Seattle, Washington: July 25
- Bethesda, Maryland: August 1
- Los Angeles, California: August 8
- Birmingham, Alabama: August 15
- Hackensack, New Jersey: September 10
- Pittsburgh, Pennsylvania: September 12

Established MDS Patient Support Groups

UNITED STATES
- Chicago Illinois Support Group meets on the fourth Tuesday of the month from 1:30–3:00 pm at Northwest Community Hospital’s Cancer Service department (lower level), 800 W. Central Road, Arlington Heights, Illinois. Contact Kim Jensen at kjensen@nch.org or call 847-618-6914.
- Puget Sound, Washington Support Group meets on the third Tuesday of the month at 6:30 pm at the Puget Sound Blood Center, 921 Terry Avenue, Seattle, Washington. Contact Steve Kessler at steve@Qamonline.com or call 800-877-0168.
- San Francisco Bay Area Support Group meets on the second Sunday of the month at 2 pm at the Park Blvd. Presbyterian Church, 4101 Park Blvd., Oakland, California. Contact 800-MDS-0839 for more information.

EUROPE (Countryside Groups)
- France: Association Connaître et Combattre les Myélodysplasies
- United Kingdom: UK MDS Patient Forum
- Czech Republic: Czech Republic MDS Forum

Ontario, Canada: September 19
San Antonio, Texas: October 3
St. Louis, Missouri: October 10
Madison, Wisconsin: November 14
Jacksonville, Florida: November 21
Cleveland, Ohio: December 12
Regional meetings in UK
(To be determined in conjunction with the MDS UK Patient Forum)
Berlin, Germany
(June 2009 in conjunction with the EHA meeting)
**Patient Advocacy Workshop**

*Raymond W. Malles*

**WOW!** If you ever have the opportunity to be a part of a Patient Advocacy Workgroup, by all means attend.

I was recently nominated (by the MDS Foundation) to participate in such an event in Morristown, NJ. This wonderful affair was hosted by the Novartis Oncology group. Its purpose was to explore new ideas for educating the uninformed; understanding and appreciating the maze affecting drug approval, and lastly, how to inform and enlist patients for participation in clinical trials. There were a total of eleven “patient advocate/survivors” — representing a broad spectrum of cancers — who were there in person or via telephone conferencing.

Our host began the process with an informal dinner the evening before we convened. It was purposefully designed to have each of us meet and greet other survivors and advocates. Each had our turn to inform others of the organization we represented. We were encouraged to tell “our story” — where we started and how we arrived where we are today. What an upbeat group of participants!

Collectively, I witnessed many clear examples of how attitude must be a principle component of survivorship, without a doubt. The paths each one travelled and the methods they employed, to reach this milestone in their journey, were profound. It was not unusual for me to silently say, “Why didn’t I think of that?” One’s “needs and desires” is a primary vehicle for motivating us to dream of ways to cope and methods to reach our goals. Have you ever heard of a survivor lobbying her legislature to establish a statewide “Lung Cancer Awareness Week”? That proclamation, along with her determination and hard work, brought much needed factual information to the forefront for the citizens of Maine. How about a video on Kidney Cancer to view on YouTube?

Aren’t these two great examples of “Can Do” for getting things done? They are just ordinary people doing extraordinary things; who saw a need; who had a desire and worked hard to make it happen. A lot of great work happens behind the scenes and thank God people like them are among us.

I had embarked on a drive to educate others, who may not know they have MDS —what it’s all about. After I was diagnosed in November 2005, my middle daughter scoured the internet seeking answers about my disease. I too am an avid computer user and benefit each day from its opportunities. I constantly seek new avenues; new experiments; new “gadgets” and new ideas. My middle daughter learned about the MDS Patient Forum to be held in Philadelphia, PA during our Christmas visit in December 2005. What an opportune time for it to occur. After all, I was just diagnosed with this insidious disease and I knew nothing about it. She, along with my wife and I, attended my first of three such forums. What an all-inclusive and informative day that was! If any of you have never attended one of the many such forums offered throughout the country, I recommend you make a sincere effort to do so. I have personally come away from each one with a deeper understanding and appreciation of this disease. You will certainly experience the same, I guarantee it.

Upon returning to Florida where I spend my winters, I decided I would seek out sources to learn all I could about MDS. I applied my computer knowledge and developed a PowerPoint slide show and “tried my luck” by convening a resident gathering in our retirement community. It turned out to be quite successful. That’s all I needed! I decided to improve upon my presentation; passed on the completed product to the MDS Foundation; and arranged for an audience in my retirement community back north.

Before departing Florida, I had the good fortune to describe my plans, for implementing my “dream,” to a friend. When I explained how I would visit local hospitals seeking funds to purchase the needed portable equipment. He asked, “How much money do you think you’ll need and hope to harvest?” I replied, “About $2,000.” What was his answer? “You’ve got it,” he responded, and he handed me a check. My angels were Glen and Sandra Blauch from Naples, Florida. From that point on, I had the tools but lacked the audience. I tried to get my foot in the door of other communities with no success. I was facing that proverbial “stone wall.”
In summary, armed with my past experience, as well as my most recent experience, I intend to alter my approach. The presentation will be completely revised as will my delivery. I’ll keep you informed as plans progress.

While the workgroup was ending and participants were saying their goodbyes, I approached two and complimented both for their past work and continuing efforts. I remarked, “We are doing God’s work.” They were somewhat surprised to hear me say that but I truly believe that they, and I, were put here on this earth for a purpose. My treatment has enabled me to lead a normal life so I should give something back. I have been blessed with certain talents and skills and it’s up to me to utilize them. Attitude, as I remarked earlier in this article, has to be positive. I like to think mine is sufficient enough to drive me forward, until my plans result in success.

While departing, I waved to everyone and remarked, “I hope to see you all again — that is, God willing and the creek don’t rise.”

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

What is MDS?
- The myelodysplastic syndromes (MDS) are a family of similar diseases that share many common characteristics and affect tens of thousands of individuals worldwide. This number reflects only those patients who are properly diagnosed. These disorders are a primary disease of the bone marrow and share several characteristics of the acute leukemias; however, MDS far exceeds any of the leukemias in prevalence. We are seeing many more cases each year and that number will increase greatly over the next decade as the baby boomers age and diagnosis improves.
- The primary cause of these disorders is unknown; however, the chemotherapy regimens that are utilized to provide curative therapy to patients with certain malignancies (lymphomas, testicular cancer, and breast cancer) can lead to the development of secondary MDS.
- Until recently treatment consisted only of supportive care including blood transfusions (red blood cells or platelets), and treatment with growth factors like erythropoietin (EPO) with G-CSF or GM-CSF. There are now three drugs approved for the treatment of MDS: Vidaza® (azacitidine), Dacogen® (decitabine), and Revlimid® (lenalidomide). At present, there are two FDA-approved drugs for the treatment of transfusion-dependent iron overload: Exjade® (deferasirox) and Desferal® (deferoxamine). None of these are curative.

How to Help:
- Bone marrow transplantation is often the only chance of survival. Nearly 70% of the patients are without a match. The need is especially critical in racial and ethnic minority groups.
- As a not-for-profit organization, the MDS Foundation depends entirely on public funding in the form of individual gifts, donations from individual and corporate entities, and membership fees to further our work.
- To learn how to support the MDS Foundation, go to the Foundation’s website at www.mds-foundation.org.

Purchase MDS Awareness Pins

The MDS Foundation has enameled lapel pins for you to wear with pride and to increase public awareness about MDS. The pins are available in either a rectangular or circular design with a $3.99 donation to The MDS Foundation.

To order your pins, call 1-800-MDS-0839.

The pins were created especially for The MDS Foundation to contribute to the effort to help people worldwide living with MDS. Your donation will help increase awareness of this little known disease, which is the most common of the hematologic malignancies. Please ask your family and friends to wear these pins in support of our mission!
A Shattered World

Samuel M. Ehrenhalt

What do you do when you find out that you have a rare, incurable disease?

It’s two years since the call. The call that was about to change everything. We were at Block and Hexter. He is kind enough to call me before he goes on vacation.

We have the bone marrow results. You have damaged chromosomes. We don’t know how to fix chromosomes.

It’s a disease I’d never heard of and couldn’t spell or even pronounce. Myelodysplastic syndromes. MDS.

What does it mean? My bone marrow doesn’t produce enough blood to keep me going. It’s like trying to grow plants in rocky soil.

Prognosis? You have damage in Chromosome 7. That’s a bad one. Many people die in the first year after diagnosis. Most within two to five. With your age, you’re not a candidate for a bone marrow transplant.

A Shattered World

There’s an immediate recognition. The old world is gone, shattered. Suddenly, you’ve been dragged to the edge. Momentarily, you glimpse the void.

It’s your first encounter with something other than just the idea that, somewhere in the far-off distance, your time will come. Somewhere along the line, the fat lady is bound to sing.

Now there is a whiff of immediacy. A new sense of being mortal.

Eleanor and I cling to each other. There are tears.

Finding Your Bearings

There is a feeling of dread that will stick with me for a while. Looking back, it was a fear of death. Eleanor works on it 24/7. My cardiologist, Alan Spiegel, will prove a major help. Putting my affairs in order, as the saying goes, is the easy part. The cemetery and such are administrative arrangements. No big deal.

But living with temporariness. That will take more complex doing. The Rav refers to initiation into the secret of non-being, based on his own experience with illness.

In his essay “Out of the Whirlwind”, Rav Soloveitchik writes: “However, this ‘fall’ from the heights of an illusory immortality into the valley of finitude was the greatest achievement of the long hours of anxiety and uncertainty. Fundamentally, this change was not an act of falling but one of rising toward a new existential awareness which embraces both man’s tragedy and his glory, in all its ambivalence and paradoxality.”

The whirlwind metaphor captures my state. Confused, turbulent, disordered. Somewhere you have to gather the strength to go beyond the stresses and worries and get to be able to face the day’s reality, make the most of it. Eleanor is a genius at it. For me it comes a lot less automatically.

At some point I stop ruminating about death and refocus on what I need to deal with and how to make the most of what I have, day by day, moment by moment. And a quick inventory showed I had a lot of pluses. The glass was still more than half full.

It’s Your Job, Man

There is recognition of responsibility. You have to deal with what you have to deal with. You’re not dying. You’re alive. Your job is not to figure how you die from it. Your job is to figure out how you live with it, how you live with a rare, incurable disease. How you live with incurable cancer. And how you keep hope alive.

You’re the only one who can do it. Support from others is important, and I get it from family, friends. Eleanor’s love and tenderness and depth of understanding are
crucial. She sees me through the rough spots, every day, all the way. She is infinitely creative.

You face the fact: it’s your job, man. In Viktor Frankl’s Man’s Search for Meaning, it’s what life expects of us: “Life ultimately means taking the responsibility to find the right answers to its problems and to fulfill the tasks which it constantly sets for us.”

Responsibility means to respond. In my case, the first task is to learn about what I’m facing. The internet yields a cornucopia of information and data. You learn that there are some 50 research centers working on MDS. Three are in New York City.

You visit a dozen websites. There is a lot of reading. You join the MDS Foundation and the Leukemia and Lymphoma Society, resource and advocacy outfits. You contact the statisticians at the National Blood Institute of the National Cancer Institute, get a feel for the quality of the data on outcomes (it’s too limited to be much good at this point in time).

**Doctors, Doctors**

You draw up a list of questions for your first appointment with the guy who did the bone marrow aspiration and biopsy. The list is sent to him a week before you’re scheduled to see him.

He’s a top flight Hematologist/Oncologist in a major New York medical center. Went to him initially because he’s touted as a doctor’s doctor: “If I had a problem, that’s the guy I’d go to.” When we meet, he goes over the ground.

He can start me on injections of Aranesp, a growth factor to stimulate blood production. There is one medication FDA has approved for this disease. Vidaza. But it has very limited success. Like 20–25 percent. And at my age, less.

My questions? He hasn’t looked at them. He turns away from his computer long enough to wave. Read the pamphlet!

I’d read that before I sent him the questions. His report goes to my internist, the referring physician, whom I’ve been with for over 20 years. A reputation as a great diagnostician. It’s two years. I haven’t heard from him yet. It’s OK. He’s long been fired!

I request a copy of the report from the Hemonc’s secretary. It’ll take a week. I settle into a chair. Tell him I’ll wait. I get it in about half an hour. The slides, in a couple of days.

It’s clear right off that this is a guy we need to get away from, pronto. In retrospect, two years later, you discern a silver lining. He was an effective stimulant for working on those fifteen items and getting them done post haste and for undertaking efforts to expand my perimeter of information on MDS, since it was evident that he’d be of no help.

You need to take control. Appointments are scheduled with key doctors in the three New York MDS research centers. We do some homework. Look ‘em up. Check ‘em out. They all are sent the by now much expanded list of questions. There are extended, informative consults with all three.

There is a fourth appointment. A prominent Hematologist/Oncologist in private practice in Brooklyn. Dr. Michael Bashevkin. Sterling credentials. The appointment is for mid-afternoon. “Mr. Ehrenhalt, you’re my last patient of the day, so take all the time you need.”

He comprehensively covers all the issues we are looking for help on. He is very impressive. He is reassuring about the numbers: “If you ask me about 100 patients, we can say something about how the outcomes will play out. If you ask me about an individual outcome, we really can’t say. Numbers can’t be applied to an individual.” I have known that for a half century. But I hadn’t been able to see it in my present situation til now.

I’m ready to go with him. But he demurs: “I want you to go to someone with a special interest in this specific disease.” Our session runs for two hours or more. “If something comes up down the road that I can help on, get back to me.” I will be everlasting grateful to him.

**Sorting it Out**

It’s decision time. It is a decision that involves commitment. Once you’re in treatment, in a clinical trial, for practical purposes, there’s no shifting. You’re in it for the duration. In fact, you initial each page of long protocol attesting to it.

We’ve gathered enough information so that I’m comfortable deciding whom to entrust with my care. There’s been a lot of reading, including published papers of the doctors I’ve had consults with. And I’m comfortable in my feelings to focus on enduring, surviving. For this round, I’m done wrestling.

Now the decision comes reasonably quickly. It’s Dr. Lewis R. Silverman at Mount Sinai Medical Center. He is forthcoming, highly skilled in getting us to understand, in a nuanced manner, complex and often subtle concepts and the way medications act on the disease and on your body.

He’s been a leading figure in MDS research and as a practitioner for many, many years, played a major role in the development of the one drug, Vidaza, now approved for my condition. He has an impressive medical team we’ve met: Ilene Schulman and Rosalie Odchimar-Reissig, universally known as Odchi.

What’s the program? His goal is to reverse the effects of the disease. That means improved bone marrow function, reducing excess blasts, immature cells that never make it, reducing the proportion of cells affected by damaged chromosomes (93 percent at the outset), and better blood counts.
Somewhere along the line he asks if I’ve ever thought about moving the clock back, to my sixties or seventies. No, been there, done that, I answer, now your job is to get me to the nineties! I’m working on it, he replies.

**Engaging the Disease**

When the disease has progressed to the point that treatment needs to begin, I enter a clinical trial. It combines the approved medication Vidaza, with an experimental drug, Vorinostat, to see if the payoffs can be improved. Vorinostat has been approved for certain kinds of Lymphoma and certain brain tumors. Now it’s being tried out for other applications.

At this writing, we’ve completed 14 treatment cycles. A cycle consists of 16 days of treatment followed by about 12 days for recovery. The deal is, we keep at it as long as there is benefit from the medication.

The treatment has some side effects, in my case mainly tiredness, weakness and a loss of appetite. They vary from day to day, from cycle to cycle. There is a general diminution of strength, energy, endurance. Fortunately, it’s a small grouping from the yard-long list of potential chemo side effects.

Whatever the phase of the cycle, mornings are a slow start. Stairs are tough. Don’t get to Minyan often. I miss that. The voice is not up to doing a Haftorah. Miss that too.

The treatment is demanding of time, periodic check-ins with the medical team, usually once or twice a week for blood counts. When transfusions are necessary it becomes an all-day affair.

**A Special Gift from Hashem**

If you’re not careful, or fail to get your head around the instructions, there can be a hefty price. In my case, a midnight altercation with a tile floor. The tile floor wins hands down. The cost: a broken nose, a smashed face, a brain bleed, eleven days in the hospital.

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**You settle into the treatment routine. They say that’s the human essence, the capacity for getting used to most anything... There are times when how you feel trumps the numbers.**

A significant setback. Eleanor’s initial take was that I was a goner. That I made it is a special gift of Hashem. Every day since should be considered a special gift.

You settle into the treatment routine. They say that’s the human essence, the capacity for getting used to most anything. Surprises are part of the routine: you have a strong day, while the numbers are weak. And vice versa. There are times when how you feel trumps the numbers.

The medical team monitors every symptom variable assiduously, rebalances the details of treatment as clinical signs change. There is a constant weighing of my response to the medications against the combination of treatment tactics needed to improve the shifting blood counts. It’s an ongoing, finely calibrated, balancing act.

**A Degree of Separation**

Early on, there is some distancing from many relationships. You find yourself apart. It’s part of being shaken up by the thought of having an incurable disease. It’s not a feeling I had with prostate cancer. To an extent you retreat for a time to those closest to you, Eleanor and the immediate family. With time and more experience with the disease, you work yourself back to your broader community.

Your path is eased by the developing relationship with the medical team and your network of connections with Mount Sinai staff: Jeannette, Linda, Miriam, George, Maureen, Betsy, Joanna, Marcelle, Muhammed, John, Ingrid, Maria, Enid. They’re important players shaping the treatment environment. They’re good and they care.

They greet me with a warm smile when I come in, arrange the paperwork on appointments. They expertly draw blood, and with my veins that takes an unusually high level of competence. They run the lab tests for blood counts and chemistries. They get me set up for transfusions, another action demanding top skills. Whatever the day, you typically feel better when you enter Mt. Sinai.

Odchi, who works with me most closely, has the details of my case at her fingertips. If creatinine levels exceed the normal range, she calls. Are you drinking enough liquids? She is alert to developing issues and responsive to questions. She puts whatever is going on into balanced, knowledgeable perspective.

Jeannette Cintron, a senior phlebotomist, and Linda Savignano Brosnan, the chief nurse of Mount Sinai’s transfusion facility, are outstanding for their consummate competence, judgment and people skills. They know how to put you quickly at ease and to develop the kind of rapport that helps you over the rough spots.

I trust Dr. Silverman. I’m thoroughly comfortable with the medical team and the total treatment environment.

**Changing Rhythms**

The disease is demanding of attention, priority and time. Blood counts get the focus you might earlier have lavished on the Dow. You struggle to make room for life beyond the treatment, to deny the disease control of your life. And that’s not a piece of cake. You stretch. In time the disease takes its place in the total picture of your life.

You negotiate with the medical team. They are caring, supportive. You get some time off. Angkor Wat is off the screen. St. Thomas fails to pass muster. We get to the Poconos, even to Florida for a week. Recently, a bonus—I’m OK’ed for a 7-day cruise to Nova Scotia. As we can, we sample the inexhaustible excitements that are New York.
After a lengthy suspension, I slowly begin working out again. Our trainer, Jerry Silverberg, develops a program for use when my capacity is very limited, another for when I can do more. Eleanor and I do Tai Chi together, following a routine she developed. More recently, there’s a step up: I join her in her weekly sessions with Jerry. Lots of stretches, weights. Get on the bike as I can.

It’s a long haul: once your muscles haven’t been challenged for months, it means starting from way back. But they have a bit of memory yet and the body responds. Its resilience is remarkable.

We make time for my usual distribution of materials on Israel and other Jewish concerns. We erect a memorial for family who perished in the Shoah. We edit a book of poems by our granddaughter Ruchama and get it published. Indeed, I clinch the deal with the publisher while in the hospital after that fall.

New intellectual adventures beckon. After a lecture, I explore the demographics and travails of Medieval Jewry, a new subject of interest to me and write a brief essay on it. There is a pile of projects awaiting attention. Several years’ work. A flowering of interest.

**Eleanor the Magnificent**

Eleanor and I are intensely happy with each other. We are more deeply in love, after more than a half century of a successful marriage. There are new pinnacles of joy in our everyday lives. It’s been a testing time and we’ve come through it with flying colors.

She is magnificent, always at the ready to respond innovatively and realistically to whatever circumstance is thrown at us. She has a sure touch for getting me through one rough spot after another.

I’ve come to a greater appreciation of the frailty of the body and the importance of strengthening your creative will to live and your feeling of hope.

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**As Jerome Groopman puts it in The Anatomy of Hope: “Hope helps us to overcome hurdles that we otherwise could not scale, and it moves us forward to a place where healing can occur.”**

As Jerome Groopman puts it in The Anatomy of Hope: “Hope helps us to overcome hurdles that we otherwise could not scale, and it moves us forward to a place where healing can occur.”

I live each day as a precious gift that Hashem has granted me.

**After a Period of Calm: Choppy Waters**

The disease? At this writing the counts are as good as they have ever been since treatment began. The white blood and platelet counts have improved. The red blood count needs periodic boosting with transfusions. I have not managed to become transfusion independent, one of the key goals of the clinical trial regimen.

The latest bone marrow results are disappointing. After some early substantial improvement in reducing blasts and the proportion of cells affected by the chromosome damage, both indicators have turned negative.

We’ve had a period of calm seas. Now we are in choppy waters. We need to change course, to take a new direction in treatment.

This clinical trial has not achieved its goals in my case. There are other options, including the possibility of other clinical trials. For now, we’re continuing the current chemo cocktail. I start the 15th cycle tomorrow.

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**Sign Up for MDS Essentials E-Newsletter**

The Foundation has created a new electronic E-Newsletter to provide healthcare professionals and patients from around the world with timely information, in a cost-effective manner. The MDS Essentials E-Newsletter is the electronic version of our quarterly newsletter. Receive up-to-date information on clinical trials, research and news by simply subscribing online at:

How could I fight something that ran through my veins? It wasn’t like it could be removed surgically. I waited until I received the literature... and asked my wife to read it. From that moment on it became our battle, I wasn’t alone...

My doctor felt if I could function at some lower hgb level (7.0) without any drugs I might avoid transfusions or at least not need as many. I didn’t know how low my hgb level would drop. Would it stop at 7.0? This is something not to try. It is a very dangerous area. This experiment put me in the hospital. If I had a weak heart it could have killed me. There was no question that transfusions were needed. What I hoped might be years away had now become the present.

I was receiving 2 units every two weeks. Transfusions would simply be managing the symptoms of the disease. As I received more transfusions I became more concerned about iron overload and the doctor discussed options with me. At one of our many discussions the doctor felt I might be a good candidate for Revlimid. After a second bone biopsy a decision to try Revlimid was made.

Using this drug, my body would be trying to attach the cause of the condition. Revlimid is a derivative of Thalidomide (Lenalidomide is a derivative of Thalidomide). The drug Thalidomide goes back to the 60’s. Forty-eight years later this drug is helping patients with MDS. Revlimid changes the bone marrow itself and makes it work more effectively. Closer to the way a normal bone marrow works. On December 29, 2007, I took my first ten milligram dose of Revlimid. The period between December 29th and March 14th was a critical time for me. I had a lot of doubt as I waited for some sign of a rise in my hemoglobin. My wonderful wife was sure it was going to work, we just had to wait. The manufacturer claims it takes 2 to 4 months to see any results. On March 14th only one unit of blood was needed. I had gone from two units to one. My first sign that something was happening, from that point on my hemoglobin level started to rise slowly.

Statistics on HGB levels taken from my CBC Lab reports:

- March 24: 8.3 HGB
- July 17: 11.9 HGB
- April 9: 9.3 HGB
- July 22: 12.0 HGB
- April 23: 9.4 HGB
- August: 12.2 HGB
- May 14: 9.7 HGB
- June 3: 10.4 HGB
- June 22: 10.7 HGB
- September 2: 12.9

August 18 we started 21 days on and 7 days off the drug.

Since transfusions were not needed I hoped my iron level would be dropping naturally. A blood test on July 17 showed my iron level had dropped 40%. Iron overload was no longer a concern. Revlimid might not be for everyone. It is a personal decision to take any drug. I have chosen to write this article that it might give hope to some one who might be thinking of taking Revlimid or one of the other few drugs available at this time. Like most drugs they don’t always work the same for everyone. And sometimes they don’t work at all. I can only tell you what this drug has done for me.

My decision to take Revlimid was based on the following.

1. FDA briefing document NDA 21-880 on Revlimid dated September 5, a thirty-nine page trial report. This document should answer any technical questions you might have about the drug and the trial study. There were also other articles I had collected about the drug.

2. My doctor who has other patients on Revlimid felt I would be a good candidate for the drug.
3. An article that I had on file dated April 4, Dr. List of the Moffitt Cancer Center in Tampa, Florida, who headed the research on Revlimid quoted, “In twenty years of dealing with patients with Myelodysplasia, we have never had anything with this magnitude of benefit for individuals that can cause a remission, particularly with just one pill.” This statement played a very important role in my decision to take Revlimid.

4. A loving wife of fifty-one years who was sure the drug would work for me. She seemed to never have any reservations that it wouldn’t work.

The one thing we all have in common is we just want to be well and do the things we were doing before we became ill. Revlimid has helped me achieve some of that, not all of it. I will never be one hundred percent again, and every day in remission is a special day. I can function quite well at a hemoglobin level of 9.7 or higher. My quality-of-life is almost back to normal. I am now back to walking, the doctor has given me permission to do light exercise. There was a time when I was transfusion-dependent that my doctor informed me that walking and exercise was off limits. I was to become a “gentlemen’s, gentlemen.” For someone who was very active this was very difficult to accept. I had to learn how to conserve energy and when to rest. Foods with iron should be cut back. I have to conserve energy and when to rest.

This involves three stages of treatment—hormones, intensive external beam radiation and the implant, in my case, of 75 radio active seeds in and around the prostate, all aimed at reducing the available area for the cancer to develop, simultaneously burning off existing cancerous tissue.

Whether or not the extremely aggressive levels of radiation applied to the prostate and surrounding bladder and bowel areas were in any way instrumental in causing damage to the bone marrow still remains conjecture, but for sure both bladder and bowel functions suffered irreparable damage and will require continuous management for the rest of my life. Until actually discredited, there seems to be justification in the proposition that the same high energy could have had some adverse effect on the performance of the bone marrow? The debate continues.

This steady deterioration of my wife’s health with Alzheimers Disease required me to become her nurse, until two years ago when she was admitted to a nursing home. Mindful of this new responsibility, I under-took a thorough Health Check five years ago and was advised that my haemoglobin levels were significantly beneath the normal spectrum of 13–18 g/dl. No symptoms were noticed at that time but, slowly, breathlessness crept in and I found myself having to stop halfway up flights of stairs to recover. Instead of leaping up escalators two steps at a time, I chose to stand still and let the machinery do the work.

The first of my many subsequent bone marrow biopsies showed the -5q syndrome, confirming an MDS condition. When my haemoglobin had descended to c. 7 g/dl fatigue had set in to such a degree that blood transfusions became necessary and there began about two years of tedious visits, at ever increasing frequency, to spend a whole day in a hospital, at three weekly intervals, absorbing three units of blood into my system.

Of course it was not long before the iron level (Ferritin) in my system had increased to in excess of 1,000 ug/l, whereupon iron
chelation therapy became essential to reduce the probability of permanent damage to any of liver, kidney and heart functions. Now, if you are a bit squeamish about hypodermic needles, iron chelation is not for you.

Picture yourself, five nights a week, puncturing your lower abdomen with a canula, securing the canula with a sticking plaster, then coupling up to a cylindrical pump which you wear for nine hours, whilst desferoxamine is infused to disperse excess iron into your bladder—your urine emerges later the colour of an orange drink!!

In the morning, the canula must be removed from a sore skin, with frequent bleeding.

As the weeks pass, the difficulty increases to find a comfortable area of skin for the next canula. The skin surface of the lower abdomen looks as if it has been exposed to attention from dozens of leeches!

This, coupled with the time and discomfort associated with the blood transfusions, places a strain upon every facet of life, calling upon reserves of optimism and resilience to defeat depression and mental capitulation to the condition. Constant rebuilding of motivation, with determination to take one day at a time become prerequisites of daily existence.

This is the time to put the whole thing in perspective. Look around any hospital environment where you happen to be and simply count the number of people demonstrably worse off than yourself, many considerably younger, and you begin to think half-full, rather than half-empty about yourself.

I have found that the more I have learned about MDS, the more rewarding are my hospital visits and here I have to pay an enormous tribute to the hospital administering and monitoring my treatment and everchanging condition.

Addenbrooke’s, Cambridge, is of course an internationally renowned hospital, and MDS Centre of Excellence, but I suggest that nowhere in the world is there a higher all round level of treatment achieved as in that part of Addenbrooke’s Haematology Department responsible for MDS patient treatment and care.

The ambience is calm and the staff ever comforting. Every aspect of treatment has an air of understatement, removing pressure and anxiety. The reality of the MDS condition is introduced slowly, on a need to know now basis, steadily building the therapy and explaining its justification.

During early discussions with the consultants relative to the prognosis of my condition, a new drug, Revlimid (Lenalidomide) was mentioned as a possible future alternative therapy to blood transfusions, to achieve an increase in haemoglobin. Revlimid already had an impressive track record in USA with the treatment of the -5q condition. This drug was relatively unknown in UK at the time, but came with such a high price that its adoption here by the health authorities was unlikely.

Now, sometimes in life you get a lucky break and so it was with me when I was introduced to the Haematology Department at Kings College Hospital, London, and subsequently accepted into a one-year clinical trial with Revlimid. The inspirational Professor Ghulam Mufti explained fully the risks and I signed an indemnity disclaimer for every side effect from a headache to death!

Regular bone marrow biopsies made visits to Kings less than comfortable but, here again, a positive attitude helped immensely and I quickly learned to relax during the biopsy procedure and simply focus my mind on the nice things in my life. Each successive biopsy became just that little more tolerable, although I’ll never know just what they did with the huge samples of bone marrow taken each visit.

The effect of Revlimid was almost immediate and my haemoglobin quickly rose from <7g/dl to >11g/dl, eventually settling at c.12.6g/dl, where it has stayed well beyond the period of the trial. It is now eighteen months since the trial concluded and I have taken neither blood transfusions nor other medication for MDS since.

With no blood transfusions necessary, there came a dramatic reduction in iron level and it was a sheer joy to be able to return unwanted supplies of desferoxamine back to the supplier. The anticipation of sleep became a pleasure again.

Exactly why Revlimid works the way it does seems difficult for anyone to explain. Why should I care! Every day is a bonus anyway!

The future looks rosy and definitely encouraging. The trinity of drugs now available, with proven capability to ease the key sources of extreme discomfort and moderate the several MDS variants are Lenalidomide (Revlimid) and Azacitidine (Vidaza) from Celgene Inc. Desferasirox (Exjade) from Novartis offers an oral alternative to desferoxamine infusion for iron chelation. All also show indication of superior cost effectiveness over existing treatment methods.

The prospect of transfusion free living with MDS has already become a reality. Where transfusions have to continue, the thresholds of discomfort and inconvenience are substantially reduced. These treatments are not a panacea, however, and some patients may experience intolerance or incompatibility. Well, you cant win them all!

The rapid rise and development of MDS Patient Support Groups around the world reflects the amazing contribution from the MDS Foundation Inc., with the indefatigable Kathy Heptinstall inspiring germination, incubation and healthy organic growth of these local collectives. Patient groups promote sharing of experience with treatment, improved education and understanding of MDS and, in many cases, can mobilize formidable pressure groups, when local government policies create barriers to the optimum procurement of drugs and other treatments.

In the longer term, the amount of fundamental research being conducted on MDS throughout the world brings hope and optimism that, one day soon, a genetic eureka will reveal a root cause and lead the way to the solution—not only for MDS, but perhaps many other genetically based, malignant diseases.

**We continue on the journey of hope.**
The Past 9 Years...

John Farquhar Monro
Scotland

The year 2000 was quite an eventful year for me. That’s when I began to have symptoms of breathlessness, tiredness, etc, which I assumed was simply a result of my age—66—or was it the outcome of the flu injection in November 2000 which knocked me out with a high temperature within two hours of injection?

I had several medical tests undertaken through 2001, which did not reveal any undue problem. I continued to be tired and listless, so I had to adjust my activities to a more leisurely and manageable pace, which proved difficult and frustrating as I always enjoyed good health and fitness.

In the early months of 2002, my condition seemed to deteriorate. I was certainly feeling much weaker—and walking up and down to my office at the Parliament took longer and longer with regular stops to recover my breath. Doctors at my local surgery decided I was anaemic and arranged for regular red blood cell transfusions which certainly helped.

I was examined and advised by the consultant haematologist at my local hospital (80 miles distant) that I had a condition known as MDS and graded as 5Q Minus. It will not kill you they assured me. Just keep getting regular transfusions, which I did. But I still felt weak and tired.

Early spring 2003, my wife Celia and my daughter Shanea Jane decided to do some internet searches to discover more details on MDS; they learned of clinical trials being undertaken at Ninewells Hospital, Dundee under the control of Dr. Bowen. We made contact and within a week we were on our way to information, treatment, and a very happy relationship.

In August 2003, I was introduced to Celgene’s Revlimed—I entailed many tests and weekly control tests. After a period of weeks, my haemoglobin count began to increase and for almost three years remained steady between 12/14 H.G. I did have a few episodes of high temperature and hospitalization due to reduced immune system, which was part of the side effects of the medicine — however I did say to Dr. Bowen at my first interview about the drug that I believed it would work — and it did.

After some 30 months on the drug, it began to be ineffective — and by April 2006 I had to go back on regular transfusions.

During the time of my high H.G. count I had a pint of blood removed every week to reduce my iron overload — following that I went on dilution medicine which did not agree with me—I am now on Ferriprox 500 mg which is very suitable and shows very little side effects. Also, I should add that I had a condition on my hands where the fingers are pulled down like a claw — now that has gone, is it the Ferriprox?

It is now 2009. I am still on transfusions every two weeks and I look forward and hope that ongoing research may lead to more lasting treatments.

John Farquhar Monro MSP
Member of the Scottish Parliament
d.o.b. 26.08 1934

A native Gaelic speaker… born and still lives in the village of Ault na Chruinn, Glenshiel Kyle Wester Ross, Scotland.

Went to Nautical college and to merchant marine service until aged 28 when ashore to be wed to Celia; one daughter and one son; an elected member of Highland Councils for 35 years until the Scottish Parliament opened in 1999. From 1974 had a civil engineering and transport company with 52 men employed… now aged 74, is threatening to retire in 2011 at the next election.

I look forward and hope that ongoing research may lead to more lasting treatments.

GIVE A GIFT OF HOPE...

Journey to Hope Bracelet

Lovin’ Kisses Beading
Promoting MDS Awareness
Sandy Madrigal, Designer/Creator
P.O. Box 2541
Davenport, Iowa 52809-2541


This handcrafted bracelet was created to draw attention to Myelodysplastic Syndromes. My design is dedicated to the loving memories of my mother, Betty and my sister, Linda. They were diagnosed with MDS, just eight weeks apart. Both fought the disease bravely and with great dignity.

Now, I’m doing what I can to continue their fight. Each bracelet is only $20.00 (plus S&H). Visit my website for details. A portion of the proceeds from the sale of my bracelets will be donated to The MDS Foundation, to help further their research and create awareness.
My Hero...

Heroes come in many different forms; some are brave, strong, or wise.

Veronica Giordano

My hero emulates all three characteristics. My Uncle Carlos personifies heroism. My uncle, who had a deep love for trains, enjoyed his employment as a New York City transit conductor and his route, which ran parallel to the World Trade Center. Ironically, it is believed by those close to my uncle, this love would lead to his untimely demise. On September 11th, 2001 when many lives were changed, destroyed, or sadly taken from their loves ones, my uncle’s life started its path to MDS. Though required to wear a protective mask while working, he was still exposed to the toxins which remained. In February 2007, my Uncle Carlos was diagnosed with myelodysplastic syndromes. Even though MDS is predominately found in men between the ages 60 and 75, my Uncle Carlos was only 43 when he was diagnosed. According to Wikipedia, MDS is caused by environmental exposure to radiation and benzene.

I was 12 years old when my Uncle Carlos was diagnosed with MDS. I was unaware of this disorder or its ramifications. What I did know was this blood disorder had a possibility to lead to cancer and that my uncle may require a marrow donor in the future. Unfortunately, I found out I was ineligible to become a possible marrow donor because of my age. That didn’t stop me. I knew I wanted to help those affected by MDS, especially my uncle. I decided to contact two companies, Jibbitz and Shoe Doodles, so that I could become a retailer. I started my first non-profit business, Roni’s Charming Clip-itz. The profits from my sales went to the MDS Foundation and that is how it all began.

I knew I couldn’t just stop there. I became knowledgeable of MDS, so that I could become an advocate and promote the awareness to others. I always displayed a homemade poster, and pamphlets, provided by the MDS Foundation, every chance I could. As the sales started to drop, I started to plan my national campaign. In the meantime, Uncle Carlos received endless blood and platelet transfusions. A few months after his diagnosis, he was hospitalized for the first time. My uncle never complained and never wanted to be an inconvenience to anyone. I truly enjoyed my phone calls with my uncle because he was sincerely interested in what I had to say. On April 23rd, 2008 we attended a marrow drive for my uncle. He was present to thank everyone who signed up. With an hour left he needed to leave to get his transfusion of platelets. I accompanied Uncle Carlos. The local news showed up and interviewed my uncle. I remember sitting there so proudly as my uncle conveyed his hopes from this marrow drive. He didn’t plead for his life to be saved. His hope was that someone else would be able to find a match, from his drive, if he was unable to. How selfless and brave was that?!

The next day, my twin brother Eric, my mom, my uncle and I went for a walk to Waterbury Park. I told my uncle about my hope to launch a national campaign. I knew I wanted to get involved with the National Marrow Donor Program. I wanted to be involved in the process of getting 1200 people signed up on the registry. My plan would be to cut one inch of my hair for every one hundred people who signed up. Therefore the name of my national campaign would be LOCS4LIFE. Uncle Carlos told me how proud he was of my plan. I also told him I would be joining the registry on my 18th birthday. I was so excited that my uncle was proud of my idea. A registered donor had been matched for my uncle. Sadly, Uncle Carlos passed away June 23, 2008, due to complications of MDS. He never got to see me start my campaign. I miss him immensely, but it makes me feel so good to know I will continue his legacy through my campaign.

To this day, I continue to bring awareness to MDS and volunteer as an Ambassador for the National Marrow Donor Program (as of April 7th, 2009 Be the Match). I am also proud that I have participated in 300 people signing up on the registry. My goal to assist in the signing up on the registry has increased to 2000. I will be launching my second non-profit business Crowning Jewels, April 2009. It will feature genuine crystal bracelets and earrings. All profits will be made to the MDS Foundation, except for those made from the awareness bracelets for other causes. I am currently in the process of having MDS Awareness ribbons made, which I designed, thanks to Ms. Audrey Hassan (MDS Foundation).

My Uncle Carlos touched countless hearts with his kindness and unconditional love. He was brave and fought a strong fight against MDS. I am not only proud to be his niece, but honored that he will always be my Uncle Carlos.

www.hope-4ever.webs.com
Daughter Raises Funds for MDS Research

Sharon and Robert Stevenson
Port Angeles, Washington

Sharon and her husband Robert competed in the San Antonio Rock ‘n Roll Marathon to help raise money in support of her mother, Barbara Thompson, in her ongoing battle with MDS.

We hope you enjoy reading their journey to raise this money to help support the work of the MDS Foundation’s journey to hope towards finding a cure for MDS.

Below are the letters that Sharon and her husband Robert sent out to family, friends, and colleagues:

Dear Friends and Family,

On November 16, 2008, Robert and I will be running in the Inaugural San Antonio Rock ‘n Roll Marathon and 1/2 Marathon. This will be my third half marathon (13.1 miles) and Robert’s fourth marathon (26.2 miles), so the running part is not new to us. What is new is this time we’re running every step to support my mother in her ongoing battle with Myelodysplastic Syndrome (MDS) and at the same time to help local cancer patients.

As many of you know, my mom, Barbara Thompson, was diagnosed in October 2007 with MDS, which is a collection of disorders in which the bone marrow does not produce enough blood cells. Normally, our bone marrow produces three types of blood cells: red (which carry oxygen), white (which help fight infections) and platelets (which help blood clot). In people with MDS, this process breaks down. Blood cells do not develop properly, and as a result, there is lack of healthy blood cells in the body. Typical symptoms of MDS include weakness, fatigue, frequent infections, easy bruising, bleeding, fevers and weight loss.

Mom has been undergoing chemotherapy five times a week every five weeks, 80 miles from her home in Grove City, Pennsylvania. This takes her and my Dad (Jack) at least four hours every trip, which is like doing a marathon every single treatment!

Fortunately, her treatments are working. Her blood counts are up, and her energy has improved between chemo treatments. We are so thankful for this.

Robert and I have a unique opportunity to join Team OMC, a fundraising group of the Olympic Medical Center Foundation, to raise money for The Myelodysplastic Syndromes Foundation, as well as our local Olympic Medical Cancer Center. We think this is a win/win because we have made a commitment to raise $4,500 and divide it equally between these two very worthy causes.

The MDS Foundation was founded on the belief that sharing information internationally about these diseases leads to progress in research and treatments, and will use the money toward their major effort of funding this international information network. This network provides MDS patients with referrals, contact names for available clinical trials, sharing of new research and treatment options, and educational support to both physicians and patients.

The money we raise for OMCC will help support our local, state-of-the-art cancer center that offers all treatments under one roof—both chemo and radiation—so that patients in our community who are fighting cancer and related diseases do not have to travel as far from home as my mom has in order to get treatments.

Throughout my mom’s diagnosis and treatment, she and my dad have been models of making the best of a difficult situation, being true partners, and figuring out how to continue to have fun together for as long as they can. We want to honor them by raising this money as partners, and training together, and then performing in an endurance race to honor those who cannot, which for us will be fun.

We are running to the finish line in honor of those competing with MDS and other cancers. If there is someone in your life we can run for, we will “carry” their names with us on the course — just let us know in your response.

Thank you for considering sponsoring us in our effort. Just as every run begins with one single step, every single dollar you send is greatly appreciated. Your generosity is tax deductible.

Warmly, Robert and Sharon Stevenson

Early December 2008

Dearest Friends and Family,

We have so much to be thankful for, and at the top of our list is YOU! : Thanks to your generosity and support of our Team OMC fundraising efforts, Robert and I raised a total of $4,574.00! This means that the Olympic Medical Cancer Center and the Myelodysplastic Syndromes Foundation have received over $1,700.00 each, and for that, and you, we are so grateful.

The most meaningful part of our trip was having my Mom and Dad there — they made San Antonio part of an autumn road trip, and spent the weekend with us. This was such a special time — we were together with brother Steve, sister Susan, Mom and Dad Corolla, North Carolina: June 2007
as much as we could be, touring all of the missions, sharing meals, and, as always, much laughter. One snafu that will go down in family history is that we missed each other after the race, due to the other 29,998 racers and their 59,996 or so support people milling around, and a missed cell phone message from us to Mom and Dad, who were waiting at the family reunion area under the letter “S” for “Stevenson,” when the unheard message had instructed them to meet at the “O” for Team “O”MC...

...We could not have had this experience without your help and donations—we simply cannot thank you enough (but we will try!). To be able to train and run in an endurance race as a part of helping cancer and MDS patients was an incredible blessing, among our many.

Here’s to a Holiday Season full of love and joy, and a 2009 to match! And, thank you again.

Warmly, Sharon and Robert

Our heartfelt thanks to the Stevenson family and congratulations on completing the course. Without the support of such dedicated people we would find it very difficult to further the causes of the Foundation as their efforts in fundraising help us immensely. If you would like to contribute in this way, or if you have a unique idea of your own, please write to us at PO Box 353, Crosswicks, NJ 08515 or call us at 1-800-MDS-0839.

Our staff of Hair Expressions
Arden Hills, MN

In March of 2008 our friend and co-worker, Sherri Koehntopp, was diagnosed with MDS.

Sherri, 66, has been a hair stylist for the past 47 years. She was known for her exceptional customer care. She was still working full time at Hair Expressions in Arden Hills Minnesota when she was diagnosed with this life-threatening syndrome. She was forced to retire much earlier than she had intended. Our staff at Hair Expressions wanted to do something for her in honor of her retirement so we decided to host a Cut-A-Thon to raise money for the research of MDS.

Our staff all worked together planning for our event notifying all the area newspapers, radio and TV stations. We collected donations from area businesses to be given out as prizes for a drawing that we held for all of our contributors on the day of our event. We served home baked goodies and refreshments to all of our guests and each of them were sent home with a thank you gift from the salon. Our event turned out to be a huge success and we were able to raise $3,100. Sherri is a very kind and giving person and we were glad we had the chance to give something back to her. Many of our guests that day were there just to show their love and support for a very dear person.

Hair Salon Sponsors “Cut-A-Thon” as MDS Fundraiser
Nutritional Health

**Food Recalls Got You Worried?**

**Spring-Clean Your Kitchen to Make it Safer**

Kitty Broihier, M.S., R.D.

Many of us take the safety of our food for granted—until a nationwide outbreak of foodborne illness occurs, or there’s a major food recall. Sometimes you can fault food growers (as with previous outbreaks involving lettuce and jalapeño peppers) and sometimes it’s the fault of manufacturers (as with the recent Salmonella contamination of peanuts originating at the Peanut Corporation of America plant in Georgia).

While you don’t have control over food safety recalls, you can control how you handle and store the food in your own kitchen. The good news is that you can change potentially dangerous habits and eat more safely—as well as avoid panicking over things that don’t involve safety. And it all starts with how you store your food. So while you’re ridding your cupboards of peanut products on the recall list (check the list at [www.fda.gov/salmonella](http://www.fda.gov/salmonella); note that major brands of peanut butter are not affected), why not overhaul the storage procedures of your entire kitchen—cupboards, pantry, refrigerator and freezer?

**Cabinets and Pantry Primer**

- **Clear it out.** Remove everything from shelves and toss cans showing any signs of leaking or bulging (signs of contamination with Botulinum, the organism that causes botulism), as well as any packages you’ve opened but haven’t used in the last six months—chances are they’re not favorites in your household anyway.
- **Check for dates.** Most packaged foods display expiration dates. But it’s important to know exactly what these dates mean:
  - **“Sell By”** date tells the store how long to display the product for sale. Be sure the date on the food you buy allows enough time to eat it before then.
  - **“Best if Used By” or “Use By”** date tells you when you should eat (or freeze) the product for best quality. Note that neither of these dates has anything to do with a food’s safety.

  It still might be perfectly safe to eat after the dates have passed—as long as it hasn’t yet been opened or mishandled (such as not being refrigerated promptly by the store or by you). Usually, it’s the quality of the food that suffers once the date has passed, so if you don’t mind a less-than-perfect texture or some separation of ingredients, it is often safe to eat—at least for a while. Once you are far past the date, however, it’s best to call the 800 number on the label to check just how long it’s safe.

  As soon as a package is opened, however, all bets are off—expiration dates don’t apply after that. Once open, bacteria can enter and spoil food in a matter of days. Typically, you should eat a refrigerated food within three to seven days of opening it, though foods like hard cheeses and condiments last a lot longer.

- **Rotate your stock.** Remember FIFO, “First In, First Out,” to ensure nothing languishes in the back of your cupboards. Organize the foods you have on hand with the oldest in front. Then, when you buy new foods, place them behind the ones you already have.
- **Keep spices away from heat, light and moisture**—that means don’t store them near the stove.
- **Store dry goods in containers with tight lids** to keep out insects.
- **Keep olive oil and nut oils away from light and heat** to preserve freshness and quality. Oils can be stored in the refrigerator, but they will thicken and get cloudy. Note: Popular garlic-in-oil combos must be refrigerated to prevent botulism.

**Refrigerator/Freezer Re-Do**

- **Toss out months-old frozen foods,** especially anything that’s freezer-burned, unlabeled or been in the freezer for more than a year.
- **Test temperatures.** Keep an appliance thermometer in the refrigerator; use it occasionally to check the freezer. The refrigerator should be 40°F or below, the freezer 0°F or below.
- **Avoid overcrowding**—circulating air keeps your fridge and freezer cooler, which means foods stay fresher longer. (Don’t keep a freezer too empty or it will have to work harder to chill the empty spaces, upping your energy bill. If not full, put anything—even unopened paper towels—in there to take up space.)
- **Don’t use the fridge door for perishables like milk or eggs; the temperature fluctuates too much. Store eggs in their carton on a shelf.**
- **Read labels and date your food.** Always check the fine print on food labels for storage suggestions—refrigeration is often necessary once a food has been opened. With an indelible marker, jot the date right on the lid or front label when you open items, so later you won’t have to guess how long they’ve been hanging around. Dating leftovers is essential, whether refrigerated or frozen.

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Chemobrain!
Is it Real?

Chemobrain. We’ve all heard the term. It refers to changes in the way many transplant survivors, and others undergoing cancer treatment, think and process information. The technical term for the problem is cognitive dysfunction and was the subject of neuropsychologist Dr. Christina Meyers’ presentation at the Celebrating a Second Chance at Life survivorship symposium hosted by BMT InfoNet and the National Marrow Donor Program in Dallas, Texas this past September.

“Chemobrain occurs in a majority of cancer patients on active therapy,” says Meyers “and persists in a substantial number of patients after treatment is discontinued. It can be caused by the cancer itself, the treatment and/or other complications such as anemia, infection or graft-versus-host disease.”

There are several components of cognitive dysfunction. Working memory, the amount of new information that can be learned at one time, may be diminished. Retrieving previously learned information may be inefficient. The ability to focus on a task or do several tasks at one time may be more difficult. However, reasoning and problem solving tend not to be affected.

These changes can have a significant impact on a person’s daily life, says Meyers. A person may become overwhelmed when more than one thing is happening at the same time, like multiple conversations. They may become easily distracted, miss key points in conversations and have trouble meeting deadlines. Performing daily tasks requires increased effort—there is no autopilot for tasks that once were routine.

So how can these problems be corrected? The first step is to identify and correct any medical problems that may be causing the condition. These include hormonal changes, thyroid problems or borderline anemia.

In some cases, drug therapy may be appropriate.

“I think our clinic hands out more Ritalin® than any school district in the United States,” jokes Meyers, “but, in fact, people who experience fatigue, attention and focus problems may really benefit from this type of medication.”

Behavioral and lifestyle changes can also improve the problem.

“Relaxation training to focus attention and exercise can help with attention,” says Meyers. “I’m not talking about going to the gym and wearing yourself out, but mild exercise on a daily basis.”

Daily planners or PDAs are extremely useful for people with cognitive problems. “Create a daily list of tasks, prioritize those that are most important and do them first. Have an end of day checklist to be sure tasks were accomplished, and use devices with audible alerts, like PDAs, to help you keep organized and on task.”

Conserving your energy can help focus and memory problems. “Pace yourself, organize tasks around the hours of the day when you are most energetic, delegate tasks whenever possible, take frequent breaks and aggressively manage sleep problems,” says Meyers.

There are a number of strategies or tricks you can use to combat forgetfulness. “If you tend to forget where you parked your car, park in the same place every day or write down the location in a daily planner. If you have trouble keeping up with your medications, use a pill box to help you remember which pills to take and when. Use direct deposit for your paycheck, appliances with automatic shut-off and phones that store phone numbers. Have a “memory station” in your home—a place where you always put important items like car keys so that they can be easily found.

What doesn’t work is repetitive tasks, says Meyers. “It’s very trendy these days to do Sudoku games, cross word puzzles or video games to make yourself more sharp. While stimulating the brain is good, it doesn’t help with the kinds of memory problems people with “chemobrain” experience. For example, if you try to do Sudoku or video games to help with your word retrieval difficulties, it won’t work. You’ll get better at the game, but not at retrieving words from your memory.” For most survivors, the chemobrain effect lessens over time, but for some it may persist for years. For people who are unable to manage the problem on their own, a consultation with a neuropsychologist may be in order. The American Academy of Clinical Neuropsychology can help you identify a qualified provider in your area. Contact them at 734-936-8269 or http://theaacn.org.

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The patient registry form has been revised and a patient authorization form has been developed to meet HIPAA guidelines. The Patient Registry will help further research into the etiology, diagnosis and treatment of MDS. Currently, the MDS Patient Registry is only accepting patients through our designated Centers of Excellence. A two page data sheet will be forwarded to investigators who wish to contribute patient’s names to the Registry. The Registry is located at the MDS Foundation’s Statistical Center at the University of Rochester Cancer Center.

The Foundation looks forward to building the Patient Registry with our Centers of Excellence. If you would like to become a Center of Excellence, please contact The Foundation at the address below.

The MDS Foundation, Inc.
36 Front Street
P.O. Box 353
Crosswicks, NJ 08515
Phone: 1-800-MDS-0839 within the US
Outside the US only: 1-609-298-6746
Fax: 1-609-298-0590.

Thank You to Our Pharmaceutical Supporters

We would like to thank our pharmaceutical supporters for their commitment to the Foundation and its work. They have contributed in the form of educational grants, which maintains not only this newsletter but also the development of the MDS homepage on the World Wide Web, the Center of Excellence program, continuing medical education programs, the Patient Registry, and the dissemination of patient information.

Be a Bone Marrow Donor

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

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

Other sites of interest:

- ASBMT™ American Society for Blood and Marrow Transplantation: www.asbmt.org
- International Bone Marrow Transplant Registry: www.isbmtr.org
- National Marrow Donor Program®: www.marrow.org
- Blood & Marrow Transplant Information Network: www.bmtinfonet.org
- Blood & Marrow Transplant Resources: www.BMTresources.org
- Bone Marrow and Cord Blood Transplantation: http://bloodcell.transplant.hrsa.gov

Over 140 Things You Need to Know about Your Autologous Bone Marrow or Stem Cell Transplant is available online at www.BMTresources.org or call 414-870-4850, ISBN#: 0-9768060-0-2/Price: $11.95. Contains over 140 invaluable tips to help transplant patients sail through their procedures.
Would you like your treatment center to become part of the referral system for MDS patients and be designated as a Center of Excellence? To be recognized as a Center of Excellence, an institution must have the following:

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

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

The following centers have qualified as MDS Centers of Excellence:

### UNITED STATES

#### ALABAMA
- University of Alabama at Birmingham
  - Comprehensive Cancer Center
  - Birmingham, Alabama
  - James M. Foran, MD

#### ARIZONA
- Mayo Clinic Hospital
  - Phoenix, Arizona
  - James L. Stack, MD
- University of Arizona
  - Arizona Cancer Center
  - Tucson, Arizona
  - Daruka Mahadevan, MD, PhD

#### CALIFORNIA
- Cedars-Sinai Medical Center
  - UCLA School of Medicine
  - Los Angeles, California
  - H. Phillip Koeffler, MD
- City of Hope
  - National Medical Center
  - Duarte, California
  - Stephen J. Forman, MD
- Stanford University Medical Center
  - Stanford, California
  - Peter L. Greenberg, MD
- UCLA Center for Health Science
  - UCLA School of Medicine
  - Los Angeles, California
  - Gary J. Schiller, MD
- University of Southern California
  - Keck School of Medicine
  - Los Angeles, California
  - Allen S. Yang, MD, PhD

#### FLORIDA
- All Children’s Hospital
  - St. Petersburg, Florida
  - Charles S. Hesdorffer, MD
- Mayo Clinic
  - Jacksonville, Florida
  - Alvaro Moreno-Aspitia, MD
  - Carlos M. deCastro, MD
- University of South Florida
  - H. Lee Moffitt Cancer Center and Research Institute
  - Tampa, Florida
  - Alan F. List, MD

#### ILLINOIS
- Loyola University Chicago
  - Cardinal Bernardin Cancer Center
  - Maywood, Illinois
  - Scott E. Smith, MD, PhD
- Robert H. Lurie Comprehensive Cancer Center
  - Northwestern University Feinberg School of Medicine
  - Chicago, Illinois
  - Olga Frankfurt, MD
- Rush University Medical Center
  - Chicago, Illinois
  - Stephanie A. Gregory, MD
  - Jamile Shammo, MD
- University of Chicago Medical Center
  - Chicago, Illinois
  - Richard A. Larson, MD

#### INDIANA
- Indiana University Medical Center
  - Indianapolis, Indiana
  - Larry Cripe, MD

#### MARYLAND
- Johns Hopkins University School of Medicine
  - Baltimore, Maryland
  - Steven D. Gore, MD
  - Charles S. Heisler, MD
- National Heart, Lung, and Blood Institute
  - Bethesda, Maryland
  - Elaine Stoian, MD
- University of Maryland Greenebaum Cancer Center
  - Baltimore, Maryland
  - Maria R. Baer, MD
  - Ivana Gojo, MD

#### MASSACHUSETTS
- Dana-Farber Cancer Institute
  - Boston, Massachusetts
  - Richard M. Stone, MD
- Tufts University School of Medicine
  - Tufts Medical Center
  - Boston, Massachusetts
  - Kellie Sprague, MD

#### MICHIGAN
- Beaumont Hospital
  - Royal Oak, Michigan
  - Ishmael Jayesimi, MD

#### MINNESOTA
- Mayo Clinic
  - Rochester, Minnesota
  - David P. Steensma, MD
- University of Minnesota Medical Center, Fairview
  - University of Minnesota Medical School
  - Minneapolis, Minnesota
  - Eric D. Warlick, MD

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

#### NEBRASKA
- University of Nebraska Medical Center
  - Omaha, Nebraska
  - Lori Maness, MD

#### NEW JERSEY
- The Cancer Center of Hackensack
  - University Medical Center
  - Hackensack, New Jersey
  - Stuart Goldberg, MD

#### NEW MEXICO
- University of New Mexico Health Sciences Center
  - Albuquerque, New Mexico
  - Robert Hromas, MD

#### NEW YORK
- Albert Einstein College of Medicine Cancer Center
  - Bronx, New York
  - Anir D. Verma, MD
- Memorial Sloan-Kettering Cancer Center
  - New York, New York
  - Stephen D. Nimer, MD
- Mount Sinai School of Medicine
  - New York, New York
  - Lewis R. Silverman, MD
- New York Medical College/Westchester Medical Center
  - New York, New York
  - Minoo Battiwala, MD
- St. Vincent’s Comprehensive Cancer Center
  - New York, New York
  - Azra Raza, MD
- University of Rochester Cancer Center
  - Rochester, New York
  - John M. Bennett, MD
- Weill Medical College of Cornell University
  - New York Presbyterian Hospital
  - New York, New York
  - Eric J. Feldman, MD

#### NORTH CAROLINA
- Duke University Medical Center
  - Durham, North Carolina
  - Carlos M. deCastro, MD
Wake Forest University School of Medicine
Comprehensive Cancer Center
Winston-Salem, North Carolina
Bayard L. Powell, MD

OHIO
Cleveland Clinic Foundation
Taussig Cancer Center
Cleveland, Ohio
Jarek Mieczkowski, MD, PhD

OREGON
Oregon Cancer Center at Oregon Health and Science University
Portland, Oregon

PENNSYLVANIA
The Western Pennsylvania Cancer Institute
Pittsburgh, Pennsylvania
James M. Rossetti, DO

Thomas Jefferson University
Kimmel Cancer Center
Philadelphia, Pennsylvania
Emmanuel C. Besa, MD

University of Pennsylvania Cancer Center
Philadelphia, Pennsylvania
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Pittsburgh, Pennsylvania
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TENNESSEE
St. Jude Children’s Research Hospital
Memphis, Tennessee

TEXAS
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San Antonio, Texas
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Houston, Texas
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University of Texas Southwestern Medical Center
Dallas VA Medical Center
Dallas, Texas

WASHINGTON
Fred Hutchinson Cancer Research Center
University of Washington
Seattle Cancer Care Alliance
Seattle, Washington
Joachim Deeg, MD/Elizhu Estey, MD

WASHINGTON, DC
Georgetown University Hospital
Lombardi Comprehensive Cancer Center
Washington, D.C.
Ekatherine Asatiani, MD

WISCONSIN
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Bone Marrow Transplant Program
Milwaukee, Wisconsin
Parameswaran Hari, MD

University of Wisconsin Madison Medical School
Madison, Wisconsin
Mark B. Juckett, MD

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Stellenbosch University and Tygerberg Academic Hospital
Cape Town, South Africa
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Hôpital Aziza Othmana
Tunis, Tunisia
Balikis Meddeh, MD

University of Cape Town
Groote Schuur Hospital
Cape Town, South Africa
Nicolas Novitzky, MD, PhD

ARGENTINA
Sanatorio Guemes
Buenos Aires University
Buenos Aires, Argentina
Marcelo Iastrebner, MD

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

University of Tasmania
Royal Hobart Hospital
Hobart, Tasmania, Australia
Raymond M. Lowenthal, MD

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University of Vienna
Vienna, Austria
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University Hospital Leuven
Leuven, Belgium
Michel Dellorge, MD, PhD

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

Hemocentro da UNICAMP
University of Campinas
Campinas, Brazil
Irene Lorand-Metzke, MD

Servico de Hematologia do Hospital das Clinicas da Faculdade de Medicina da Universidade de Sao Paulo
Sao Paulo, Brazil
Elvira R.P. Veloso, MD, PhD

Univerdade Federal de Ceará
Ceará, Brazil
Silvia Maria M. Magalhaes, MD, PhD

Univerdade Federal de Sao Paulo
Sao Paulo, Brazil
Maria de Lourdes Chauffaille, MD, PhD

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

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

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

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

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

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

DENMARK
Odense University Hospital
The University of Southern Denmark
Odense, Denmark
Gitte Birk Kermstrup, MD

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

University of Århus
The University Hospital Århus, Denmark
Johan Lann Nielsen, MD, PhD

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

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

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

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

Centre Hospitalier Universitaire de Nancy
Nancy, France
Agnée Guerci-Bresler, MD, PhD

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

Hôpital Claude Huriez, CHU Lille Service des Maladies du Sang
Lille, France
Bruno Quesnel, MD
International Clinical Trials: An Update

NATIONAL CANCER INSTITUTE TRIALS

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

- Log on to www.nci.nih.gov
- Click on “Finding Clinical Trials”
- On the next screen look for “Ways to Find Clinical Trials” and
- 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. You can also contact 1-800-4-CANCER for more information.

If you are an MDS patient, you may wish to discuss a trial with your primary treating physician to see if you qualify as a candidate.

Clinical trials often have very specific eligibility requirements. Please talk with your doctor to help decide which, if any, trials might be right for you.

Please note that the information is provided strictly as a resource and is not an endorsement of any physician, institution or treatment.

New Research Protocol Listings

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS and has updated its International Clinical Trials list on our website and for distribution. Please contact us for a detailed listing featuring new protocols:

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

Clinical trials often have very specific eligibility requirements. Please talk with your doctor to help decide which, if any, trials might be right for you.

Please note that the information is provided strictly as a resource and is not an endorsement of any physician, institution or treatment.

Insurance and Drug Reimbursement Resource Guide

We have assembled a listing of insurance and drug reimbursement resources for MDS patients. It is important to know that there is support for those who cannot afford medicine or other healthcare costs. We hope this new resource will be beneficial in helping you with your medical needs.

This guide to assistance programs in the United States is available for download from the Foundation’s website or can be ordered in booklet form upon request.
A CRITICAL NEW CLINICAL TRIAL

Myelodysplastic Syndromes (MDS) and Anemia: Potential New Treatments Through Clinical Research

The MDS Foundation is active in supporting MDS patients including maintenance of access to therapy with erythropoietin-stimulating agents (ESAs). Johnson & Johnson Pharmaceutical Research and Development (J&JPRD) has structured the EPOANE3018 protocol with input from the FDA to demonstrate the benefit and safety of epoetin alfa treatment in MDS patients.

Research to date suggests that epoetin alfa is effective in reducing the need for red blood cell transfusions in patients with early stages of MDS. The purpose of this study is to explore whether it will decrease the need for blood transfusions and increase the hemoglobin level in patients with early stage MDS and anemia. While the Centers for Medicare and Medicaid Services (CMS) did not make MDS a part of their original decision due to the ‘definition’ that MDS is not cancer, the Foundation strongly feels that this will not be the case in the long term.

Many MDS patients rely on ESAs for the management of their disease. This trial will play an important part in decisions that will determine the future treatments for MDS patients. The use of this supportive and comprehensive data can then serve to have a positive influence over future decisions by CMS or to possibly change the labeling for ESAs to include approval for use in bone marrow failure diseases by the FDA.

EPO-ANE-3018 Study

Anemia (a drop in the body’s red-blood-cell count) is the most common blood abnormality in the early stages of MDS. Treatments that can reduce or delay the need for blood transfusions may improve and extend better quality of life for persons with early stage MDS. More research is needed to evaluate such treatments and to obtain FDA approval for use in patients with early disease who are not yet transfusion dependent.

In the EPO-ANE-3018 study, epoetin alfa will be evaluated in patients with early stage MDS, who are not yet treatment dependent, to see if it can delay the need for transfusion. Transfusion dependence is defined as the requirement of an average of two units of adult sized red blood cell units per month. Patients with early stage MDS who have no or low red blood cell transfusion requirements are included in this study because there currently are limited treatment options for MDS patients who have anemia but are not requiring red blood cell transfusions on a regular basis.

Research to date suggests that epoetin alfa is effective in reducing the need for transfusions in patients with early stages of MDS. Epoetin alfa is a manufactured form of the human hormone erythropoietin, which stimulates the production of red blood cells.

Epoetin alfa is distributed in the United States, the European Union, and other countries under several brand names including PROCRIT®, EPREX®, and ERYPO® for the treatment of other related disease conditions.

If you are a patient with early stage MDS and anemia who is not yet transfusion dependent or a health professional caring for a patient, and would like to receive more information about this study, please refer to the contact information at the end of this article.

What is the purpose of this study?

The purpose of the EPO-ANE-3018 clinical research study is to explore the use of epoetin alfa, to see if it will decrease the need for blood transfusions and increase the hemoglobin level in patients with early stage MDS and anemia.

Who qualifies for this study?

To qualify for this study you must:

- Be at least 18 years of age
- Have been diagnosed with MDS
- Have an International Prognostic Scoring Systems (IPSS) score of Low- to Intermediate-1 Risk Disease
- Have anemia (a hemoglobin count of 10 g/dL or below)
- Not transfusion dependent (<4 red blood cell units during a consecutive 8-week period) in the past 6 months

What can you expect if you are eligible and enroll in this study?

- Before any study related procedures are performed, the study doctor will discuss the study in detail with you, including any potential risks or benefits.
- If you participate, you will be randomly assigned (by chance, like flipping a coin) to one of three investigational treatment schedules:
  - Epoetin alfa 40,000 IU (1 mL) given once a week by subcutaneous (under the skin) injection
  - Epoetin alfa 80,000 IU (2 mL) given once a week by subcutaneous injection
  - Placebo given once a week by subcutaneous injection. Half of this group will be assigned to 1 mL dosing and the other half will be assigned to 2 mL dosing.
- You will visit the study center each week during a 48-week Study Treatment Phase for blood tests, assessment of disease progression, to receive study drug and periodic measurement of iron stores.
- You may continue to receive the investigational study drug beyond the 48-weeks if you do not require transfusions and your doctor feels that you are benefiting from the treatments.
All patients will receive current standard of care for anemia management.

You will continue to have safety evaluations for 4 and 1/2 years following study participation. These visits for the most part should coincide with routine scheduled visits to your doctor for your condition.

For doctors caring for a patient(s) with early stage MDS who may be a candidate(s) for this study:

Approximately 450 subjects will be randomly assigned to one of the study drug schedules

The Study Phases Include:

- Pre-randomization (Screening) Phase: Day –1 to –14
- Study Treatment Phase: Day 1/Week 1 to Week 48
- Safety Assessment Phase, consisting of:
  - Short Term Safety (Week 52) or Early Withdrawal from treatment visit
  - Long Term Safety Assessments — until progression to AML, death, or the clinical cutoff is reached whenever occurs first

An Independent Data Monitoring Committee (IDMC) will periodically review overall safety data throughout the study.

An Independent Central Pathology Reviewer will review bone marrow samples and peripheral blood counts for assessment of disease progression.

To learn more about participating in the EPO-ANE-3018 study or to refer a patient to this study, please contact the MDS Foundation by E-mailing us at: CTC@mds-foundation.org or by calling our toll free EPO-ANE-3018 study number: 1-888-813-1260 (within the US) or 609-298-7741 (outside of the US).

We look forward to talking with you and working together to find new and better treatments for patients with early stage MDS.

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### About the Foundation

#### Who Are We?

The Myelodysplastic Syndromes Foundation, Inc., was established in 1994 by an international group of physicians and researchers to provide education about MDS to physicians and patients, support for MDS research, patient support and advocacy. During the past decade, we have independently solicited funding for ten international symposia that have been attended by over 7,000 individuals — physicians and patients. These symposia are held biannually and have greatly improved our knowledge of these disorders and continue to provide physicians worldwide with the most up-to-date information on research in MDS. The 10th International Symposium will be held in Patras, Greece May 6–9, 2009.

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

#### What Does the Foundation Do?

The Foundation works to maintain an international information network to share new research and new treatment options as rapidly as possible, to provide information and educational support for both physicians and patients, and, ultimately, to provide funding and oversight for international studies of MDS. Currently the Foundation supplies patients, physicians, and other interested parties with information in the form of a quarterly newsletter, The MDS News and MDS Essentials our e-newsletter. The Foundation’s website includes patient and physician information. Our web address is http://www.mds-foundation.org.

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

Patient Advocacy groups are being formed worldwide and information is available that assists MDS patients and their loved ones to understand these diseases and the treatment options that are available.

#### How Can You Help?

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

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

#### How Can We Help You?

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

**MDS International Headquarters:**

- **US Patient Liaison**
  - 36 Front Street, PO Box 353
  - Crosswicks, NJ 08515
- **Outside the US:** 1-800-MDS-0839
- **EU Office:**
  - EU Patient Liaison
  - The Rayne Institute
  - 123 Coldharbour Lane
  - Denmark Hill Campus
  - London SE5 9NU, UK

**Tel/Fax:** +44 20 7733 7558

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**EU Patient Liaison**

The Rayne Institute

123 Coldharbour Lane

Denmark Hill Campus

London SE5 9NU, UK

Tel/Fax: +44 20 7733 7558
Educational Resources

Understanding MDS: A Primer for Practicing Clinicians

Visit www.mds-foundation.org and click on The MDS Foundation Resource Center to take advantage of this comprehensive program, and other informative programs coming soon, designed to provide you with tools and information that will assist you in administering the best care to your patients.

Segment 1 – The Past & Present in MDS
Segment 1 provides insight into the history of MDS, development of the MDS classification and prognostic systems, and a glimpse into the future of MDS diagnosis, research and treatment.

Segment 2 – Clinical Presentation, Diagnosis & Pathology
Segment 2 provides insight into the clinical picture of adult and pediatric MDS, primary and secondary MDS, FAB and WHO Classification system, and rationale for the proposed MDS pediatric classification system.

Segment 3 – Ineffective Hematopoiesis: Considerations in Diagnosis & Treatment
Segment 3 provides insight into the pathogenic mechanisms that contribute to the development of MDS, including the altered bone marrow microenvironment of MDS in terms of cells, cytokines, growth factors, receptors, and microvasculature; dyserythropoiesis in MDS, and therapeutic targets and approved drugs for the treatment of MDS.

Segment 4 – Anemia in MDS: Survival, QoL, and Treatment Options
Segment 4 is an overview of supportive care with a focus on RBC transfusions and its effect on the morbidity and mortality of MDS patients. This segment also looks at the quality of life issues from the perspectives of the physical, functional, emotional, social and cost impacts on the patient with MDS.

Segment 5 – Treatment Strategies in MDS – Coming Soon!
Segment 5 provides an overview of the patient management approaches for MDS. The segment looks at currently approved or licensed treatment options available to MDS patients and patient selection criteria associated with each treatment. The segment also looks at the mechanism of action for emerging MDS therapies in clinical trials and the evolving role of combination therapy in MDS.

This multi-segment program will allow participants to choose the segments that interest them and to learn at their own pace. Segments may be completed via a written program, online in our technologically advanced MDS Foundation Educational Center, or via CD-ROM on their personal computer. This multi-segment program is available in the following languages: English, French, German, Italian, Japanese and Spanish.

The program is approved for 1 hour of CME credit upon completion. There is no charge for this educational activity.

The Myelodysplastic Syndromes Foundation strives to serve as an effective conduit for information regarding the most updated treatment options, clinical studies, referrals to Centers of Excellence, and other information concerning MDS. Please bookmark our site, www.mds-foundation.org, and check back frequently for new, informative programs.
Myelodysplastic Syndromes: Clinical and Biological Advances
Peter L. Greenberg, MD
Stanford University Medical Center

As the current major comprehensive reference on all aspects of the clinical classification underlying pathogenetic mechanisms and treatment of the myelodysplastic syndromes, Myelodysplastic Syndromes stands out as the definitive text on the genetics, pathophysiology, and clinical management of this wide range of syndromes. Authored by international experts, this book provides a state-of-the-art update of the current status and recent advances in the field. The chapters cover all aspects of the myelodysplastic syndromes, from an in-depth analysis of the multifactorial nature of this disease, including a careful assessment of stromal, immunological and stem cell abnormalities, to a review of recent molecular and cytogenetic discoveries and insights.

This book will be a valuable resource to clinicians and researchers who wish to learn more about myelodysplastic syndromes.

Myelodysplastic Syndromes & Secondary Acute Myelogenous Leukemia: Directions for the New Millennium
Edited by: Azra Raza, MD; Suneel D. Mundle, PhD
June 2001/278 pp., illus.
ISBN: 0792373660/$198.00** Springer Science+Business Media, Inc.

Myelodysplastic syndromes are to the bone marrow what pneumonia is to the lungs; the response of an organ to a variety of etiologic insults like aging, toxic exposure, infections and auto-immunity. Among infectious causes alone, pneumonia could be the result of a variety of possible pathogens including bacterial, viral, tuberculous or fungal agents. Similarly, MDS cannot be treated as a single disease. Attempts to harness the inherent complexity of MDS by devising “classifications” which group the various syndromes as one disease is as misguided as saying that a pneumonia is not infectious because it did not respond to antibiotics. Progress in the field will occur faster when we re-analyze this premise. Therefore, until a clearer picture of the disease emerges it is best to treat each of the MDS syndromes as a separate entity. Having no classification is better than a misleading one. This book is our attempt to define the most crucial questions related to MDS that need to be addressed immediately through logic, analysis and rigorous experimentation. If the emerging problems appear daunting, then instead of being overwhelmed by them, we should follow the advice of the great 20th century thinker Antonio Gramsci, “pessimism of the intellect must be faced with the optimism of will”.

Myelodysplastic Syndromes, Second Edition: Pathobiology and Clinical Management
Edited by: David P. Steensma, MD
November 2008/536 pp., illus.
ISBN: 978-01420074390/$225.42** Informa HealthCare

This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse environmental and genetic factors, and efficient modalities of supportive care that improve patient survival and enhance quality of life.

Myeloproliferative Disorders: Biology and Management
Edited by: Richard T. Silver, MD; Ayalew Tefferi, MD
October 2007/240 pp., illus.

Myeloproliferative disorders, written by international renowned experts in the field, examines:

– New and developing diagnostic protocols and algorithms and supportive care regimens
– The evolution and classification of recent myeloproliferative disorders
– Advancements and the implications arising from clinical care and practice
– The activating JAK2V617F developed in a chapter by top experts
– The overlap between myeloproliferative disorders and myelodysplastic syndromes
– The importance of histopathology and cytogentic discoveries and insights

With the recent discovery of JAK2 mutations in myeloproliferative disorders, medical science has taken a revolutionary stride forward toward understanding the pathogenesis of these diseases. This new advancement translates not only to a more rapid and reliable diagnosis, but also allows groundbreaking research into the development of new therapeutics. Written in an easy-to-follow text myeloproliferative disorders gives the practicing clinician a single source answer to classification, diagnosis, management, and recent advances in this disorder.
100 Questions & Answers About Myelodysplastic Syndromes

By: Jason Gotlib, MD, MS; Lenn Fechter, RN, BSN

December 2007/172 pp., illus. ISBN: 9780763753337/$19.95**

Jones and Bartlett Publishers: 800-832-0034; www.JBpub.com

Whether you’re a newly diagnosed patient, a survivor, or loved one of someone suffering from MDS, this book offers help. The only text available to provide both the doctor’s and patient’s views, 100 Questions & Answers About Myelodysplastic Syndromes, provides practical, authoritative answers to 100 of the most common questions asked. Written with commentary from actual patients, this is an invaluable resource for anyone struggling with the medical, physical, and emotional turmoil of this disease.

**All prices are in US dollars.

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

TERMS OF THE OFFER:
All individual orders must be prepaid by check or money order or charged on Visa, Mastercard, or AmEx. Canadian residents, please add 7% GST. Residents of CA and NY, please add local sales tax.
Shipping and handling charges for North America are $6.00 for the first book and $1.75 for each additional book. Outside North America (only credit card orders accepted) — $9.00 for first book; $5.00 for each additional book.

Highlights of Latest Literature in MDS

Suneel D. Mundle, PhD

Listed below are citations of some new publications relevant to MDS (pathogenesis, clinical characterization, management, etc.). To access the complete article log on to www.pubmed.gov.

MD5 OVERVIEW & PERSPECTIVES:

A review of hemizygous interstitial deletions of chromosome 5q and importance of RPS14 in erythroid failure

This editorial describes diagnostic challenges between myelodysplasia that could arise as a sequel to other conditions as opposed to a true myelodysplastic syndrome and suggests a caution in the use of these terms.

This editorial sheds light on survival benefit regardless of complete marrow response in determining the benefits of therapy.

This perspective building article reviews common biologic and treatment traits of MDS and AML, and eventually draws a parallel with the evolution of chronic phase of CML into blast crisis.


This review details major features and methods used to assess comorbidity and its role in altering prognosis in MDS patients. As such, it provides information for assessing this parameter for possibly modifying current prognostic scoring systems.

DIAGNOSIS AND PROGNOSIS:

A retrospective analysis of 351 consecutive MDS patients studied for histology, demonstrated moderate to severe marrow fibrosis in 17% cases, which was associated with multilineage dysplasia, high transfusion requirement and poor risk cytogenetics. These patients also demonstrated poor survival rates. CD34+ clusters were detected in 23% specimens and seemed to have an independent prognostic value.

In 65 of the total 109 MDS patients studied from the Duesseldorf registry, plasma concentration of beta-2-microglobulin ≥ 2 mg/dL was correlated with significantly lower overall survival and a higher risk of evolution to AML.

This report provides specific details regarding the impact of the depth of cytopenias on clinical outcomes in patients evaluated within the International MDS Risk Analysis Workshop database—which generated the IPSS. These data will be helpful in refining the IPSS for
prognostic utility and for determining the potential levels of these low blood counts when designing clinical trials with hematopoietic stimulants.

TREATMENT:

General:
A retrospective matched-pair analysis was performed on patients from the Duesseldorf MDS registry to assess the impact of different treatments on overall survival. Thalidomide, Valproic acid, and ATG showed significantly prolonged survival as compared to supportive care (that included erythropoiesis stimulating agents). The survival advantage with these agents was particularly evident in intermediate to high risk patients.

Growth Factor:
This literature meta-analysis of prior reports on epoetin-alfa showed significantly higher erythroid response rates using IWG 2000 criteria with higher doses of epoetin (60,00–80,000 U qw) as compared to the standard oncology dose of epoetin (30,000–40,000 U qw) alone or in combination with G-/GM-CSF.
A combination of ATRA with epoetin-beta was found efficacious in eliciting erythroid response in patients who failed prior treatment with erythropoietin or had endogenous serum EPO >500U/L.
A total of 63 low/intermediate-1 risk MDS patients were treated with a combination of 13-cis-retinoic acid+ dihydroxylated Vitamin D3 ±6-thioguanine in addition to epoetin. Most patients (70%) were transfusion dependent. The erythroid response rate was 60% with a median duration for response being 16 months. The responders showed significantly higher median survival vs. non-responders (84 mo vs. 44 mo. respectively)
Intra-patient dose escalation was undertaken in 24 primarily low/intermediate-1 risk MDS patients in three 6-week dose cohorts until a major erythroid response was seen, i.e. 4.5 mcg/kg/week → 9 mcg/kg/week → 9 mcg/kg/week +G-CSF. The median starting dose of darbepoetin in all patients was 390 mcg/ week and was higher for RARS patients (730 mcg/week, n=9). The overall erythroid response rate was 67% and median duration for response in major responders was 11 months.

Demethylating Agents:
In this pivotal phase III trial, intermediate-2/high-risk MDS patients (N=358) were randomized to receive azacitidine at 75 mg/m2/d sc x 7 days q28d cycle or conventional care (supportive care or low dose cytarabine or intensive chemotherapy). The primary endpoint was overall survival. Treatment cross-over and the use of erythropoiesis stimulating agents were not permitted. On treatment arm patients received a median of 9 cycles of azacitidine. After a median follow up of 21.1 months, the overall survival was superior for azacitidine (24.5 mo) as compared to those receiving conventional care (15 mo) with estimated 50.8% vs. 26.2% 2-year survival rates respectively. Patients with chromosome 7 abnormalities also demonstrated survival advantage with azacitidine.
Three dosing schedules were assessed primarily in lower risk MDS for 4-week cycle of azacitidine, i.e. aza 5-2-2 (75 mg/m2/d sc × 5d on-2d off-2d on) or aza 5-2-5 (50 mg/m2/d sc × 5d on-2d off-5d on) or aza 5 (75 mg/m2/d sc × 5d).
All three dosing schedules demonstrated comparable hematologic improvement rates, RBC transfusion independence and safety profile. Moreover, the results were in line with the current labeled dose.
This retrospective study evaluated efficacy of azacitidine (75 mg/m2/d× 7 d q28d) given for a median of 4 cycles. The overall response rate was 50% with 15.6% CR, 34.4% SD and 25% HI. Responding patients showed significantly longer time to leukemic transformation (45 weeks vs. 14 weeks respectively) and prolonged overall survival (74 weeks vs. 26 weeks respectively) as compared to non-responders.
Iron Management:

A retrospective case-controlled outcomes study using a large US health-insurance claims database (1997–2004) with a total of 4546 patients, showed significant evidence of association of blood transfusions with iron overload.

Costs:

This study details the specific costs of drugs used to treat MDS patients in the U.S. according to guidelines recommended by the NCCN MDS panel. The substantial costs of drugs and supportive care described for such treatment need to be considered in assessing the potential for control of the high costs of medical care for these patients.

Pathobiology:

Autoimmune disorders have in the past been associated with a risk of lymphoproliferative disorders. This article demonstrates clear association of AML and MDS with several autoimmune disorders including rheumatoid arthritis.


A correlation of overall survival was seen with increased expression of six genes encoding for proteasome subunits in the bone marrow derived CD34+ cells from MDS patients. The CD34+ cells also showed downregulation of anti apoptotic IEX-1 gene.


The current study retrospectively assessed cytogenetics in 351 Chinese adult patients with primary MDS demonstrating 67.5% cases with different chromosomal abnormalities. Besides the known MDS-related chromosomal abnormalities, the study demonstrated rare translocations in approximately 4% and i(17)(q10) in 3% cases. The rates of trisomy 8 also were higher than those seen in western population.


This study demonstrated that both stromal contact and a co-presence of TNF-α are essential for induction of apoptosis in hematopoietic progenitors of MDS marrows. Importantly, the study also showed that the apoptosis was dependent on PYCARD gene expression.


This study assessed DNA methylation using microarrays and found increased frequency of gene methylation with blast transformation. Of the total 1505 Cpg loci, 91 were methylated in early MDS, while 179 were methylated in RAEB/AML cases. Among the frequently aberrant methylated genes, FZD9 tumor suppressor gene on chromosome 7 was identified as a key gene associated with poor outcome.

We would like to thank Suneel Mundle, a member of the MDS Foundation, for his assistance in monitoring these important peer-review publications on MDS.
MDS Foundation Publications

MDS Handbooks Now Available in Multiple Languages
- Understanding Myelodysplastic Syndromes: A Patient Handbook

In addition to English, the Handbook is available in the following languages:

- Arabic
- Czech
- Dutch
- French
- German
- Greek
- Hebrew
- Hungarian
- Italian
- Japanese
- Polish
- Portuguese
- Romanian
- Russian
- Spanish
- Swedish
- Turkish

- Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients

In addition to English, the Handbook is available in the following languages:

- Arabic
- Czech
- Dutch
- French
- German
- Greek
- Hebrew
- Hungarian
- Italian
- Japanese
- Polish
- Portuguese
- Romanian
- Russian
- Spanish
- Swedish
- Turkish

New MDS Publications Coming Soon...
- What Does My Bone Marrow Do?
- Myelodysplastic Syndromes in Children: A Family Handbook
- It Takes Time to Realize Your Goals
- EZ Tracker

Patient Information & Educational Materials Available from The MDS Foundation
- The MDS News
- MDS Essentials: Foundation’s E-Newsletter
- Patient Diary
- Understanding Myelodysplastic Syndromes: A Patient Handbook
- Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients
- Insurance and Reimbursement Resources for MDS Patients

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

Gifts to the Foundation

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

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- Norma Weinberg, Margate, NJ
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- Henry Blume, Menno Park, CA
- Monroe Bank & Trust, Monroe, MI
- Julia Cochrane, Chicago, IL
- Dr. Paul M. Nemiroff, Gibsonia, PA

Ways to Support the Foundation’s Work All Year Long...

Individual donations of any amount.
Every penny helps.

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

If you wish to support the work of the Foundation in the battle against myelodysplastic syndromes, please remember us and consider donating all year long. All donations are tax-deductible. Thank you for your support.

Eileen R. Dunne, Kingston, MA
Jennifer A. Robles, Camarillo, CA
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Katrin A. Gerig, Fishers, IN
Mike and Amy Nesfeder, Bethlehem, PA
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Lara, Nick, Elizabeth, Zoe & Hope Mann, Fishers, IN
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David Karam, Otisco, NY
Ed Pickard, Highland Beach, FL
Gerald and Polly Clements, Auburn, ME
Christine Zwiebel, Randolph, NJ
Lila Wanderman, Las Vegas, NV

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A Living Endowment

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

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

A Living Endowment donation has been made in honor of: Sherri Koehntopp’s Retirement

This donation was submitted by:
Thomas & Susan Masso, New Brighton, MN
Joseph & Lynne Ardolf, Stillwater, MN
Patricia J. Ward, Mounds View, MN
Coreen A. Elwell, Coon Rapids, MN
Kathleen L. Carlson, Ham Lake, MN
Kitty C. Johnson, Shoreview, MN
Mary Jane DeWitt, Shoreview, MN
Jill K. Lund, Roseville, MN
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Cynthia Hanson, Shoreview, MN
Beverly Flaherty, Arden Hills, MN
Vibrant Dental, Shoreview, MN
D. Bagin, Inc. Hair Expressions, Arden Hills, MN
Jean Olson, Shoreview, MN
Corrine De Laitsch, Shoreview, MN
Mary E. Richardson, Arden Hills, MN
Karen L. Eckman, Shoreview, MN
Dorothy Borgstrom, Saint Paul, MN
D. D. Koehntopp, Blaine, MN
Susan Davis, Oakdale, MN
Patricia Maurer, Shoreview, MN
Mildred Janssen, Shoreview, MN
Betty Lou Lindholm, Shoreview, MN

A Living Endowment donation has been made in honor of: Virginia S. Godoy’s 85th birthday

This donation was submitted by:
Marlene Godoy, DDS, Irvine, CA

A Living Endowment donation has been made in honor of: Mary Leccese

This donation was submitted by:
Jo-Ann and Phyllis Leccese
Howard Beach, NY

A Living Endowment donation has been made in honor of: Barb Davis – Davis Christmas Charity

This donation was submitted by:
Michael & Julie Cossette, Lexington, KY
Sally Davis, Tallahassee, FL
Joel and Alison Gooch, Alpharetta, GA
Susan M. Gooch, Fishers, IN
Katrin A. Gerig, Fishers, IN
Mike and Amy Nesfeder, Bethlehem, PA
Doug Holmes, Louisville, KY
Joe and Barbara Davis, The Villages, FL
Lara, Nick, Elizabeth, Zoe & Hope Mann, Fishers, IN
Mark & Tracey Holmes, Lawrenceburg, IN
Thomas & Mary Beth Davis, Columbus, OH
Joseph C. Davis, St. Augustine, FL
Eric and Jenn Geldhof, Lexington, KY

A Living Endowment donation has been made in honor of: Andrea Greene

This donation was submitted by:
Sherry Thomas, Benvyn, PA

A Living Endowment donation has been made in honor of: Leonard Bini’s 70th Birthday

This donation was submitted by:
Gordon & Janet Cunningham
Indian Wells, CA

A Living Endowment donation has been made in honor of: James Maltas

This donation was submitted by:
Greg Blair & Pam Howell, Johnson City, TN
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Mr. Jeremy R. Alloway
Donations have been made in Mr. Alloway’s memory by:
Debra Alloway, Powell, OH

A memorial fund has been established in the name of
Mrs. Linda Alves
Donations have been made in Mrs. Alves’ memory by:
Frank R. Alves, Gicoty, CA

A memorial fund has been established in the name of
Mr. Jadranko Andrin
Donations have been made in Mr. Andrin’s memory by:
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Flushing, NY
Solija Vucenik, Virko and Kalca Jakolis
Flushing, NY
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Whitestone, NY
Josko and Mirjana Roman
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A memorial fund has been established in the name of
Ms. Kaete Angel
Donations have been made in Mrs. Angel’s memory by:
George & Angie Kohlweiler
Elizabethtown, PA
Michael and Paula Deutsch
Cranbury, NJ
The Christian Family
Westbury, NY
Mary O’Connell
Bethel, CT

A memorial fund has been established in the name of
Ms. Jan Baclawski
Donations have been made in Ms. Baclawski’s memory by:
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Rosemary Baclawski
Beacon Falls, CT
Garry and Cynthia Walsh
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Sequim, CT
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Kevin and Catherine Griffith
Middletown, CT
Barbara Shepperd
Shelton, CT
James and Maureen Hancock
Trumbull, CT

A memorial fund has been established in the name of
Ms. Elizabeth Mary Barbieri
Donations have been made in Ms. Barbieri’s memory by:
Jeanne E. Dove
Mechanicstown, MD
Jasper and Sylvia Tucker, Therese Kirkland, Annapolis, MD

A memorial fund has been established in the name of
Mr. Arthur H. Baron
Donations have been made in Mr. Baron’s memory by:
Ann May Greene, Wyncote, PA

A memorial fund has been established in the name of
Ms. Pauline Barth
Donations have been made in Ms. Barth’s memory by:
Irene Jacobs, Merritston, NJ

A memorial fund has been established in the name of
Mr. Seymour Baum
Donations have been made in Mr. Baum’s memory by:
Joel and Nancy Kremsdorf
New York, NY
Marcello & Elizabeth Halpern
Oak Park, IL
Rick and Abby Satel
River Edge, NJ

A memorial fund has been established in the name of
Ms. Dorothy Bayer
Donations have been made in Ms. Bayer’s memory by:
David Bayer, Bourbonnais, IL

A memorial fund has been established in the name of
Dr. William Beck
Donations have been made in Dr. Beck’s memory by:
Friends @ FAMILIAS
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Orlando Jardini
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Ms. Elizabeth Bell
Donations have been made in Ms. Bell’s memory by:
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David Wilson Duff
Salem, OH
Wes and Irene Godd, Mount Vernon, OH

A memorial fund has been established in the name of
Mr. Stanley M. Bennett
Donations have been made in Mr. Bennett’s memory by:
Reuben and Mary Erickson
Naples, FL
John and Marge Suedbeck
Naples, FL

A memorial fund has been established in the name of
Mr. Donald R. Bills
Donations have been made in Mr. Bills’ memory by:
Alan and Frances Rudman, Wilbraham, MA

A memorial fund has been established in the name of
Mr. Edwin Bolin
Donations have been made in Mr. Bolin’s memory by:
Suzanne Rinne
Louisville, KY
Garry and Carm Caudill
Pine Valley, AZ

A memorial fund has been established in the name of
Mrs. Robert W. Bowen
Donations have been made in Mr. Bowen’s memory by:
Michael Nogas, Glastonbury, CT

A memorial fund has been established in the name of
Mrs. Laura Boyd
Donations have been made in Mrs. Boyd’s memory by:
Lori Bailey
Blanchard, OK
OU Medical Center Lab
Oklahoma City, OK

A memorial fund has been established in the name of
Ms. Ann Byrne
Donations have been made in Ms. Byrne’s memory by:
Mary P. Byrne, Chicago, IL

Suzanne Fleischman
Memorial Fund for Patient Advocacy

A fund has been established by the MDS Foundation in memory of Suzanne Fleischman. Contributions may be sent to the Foundation with a notation designating the Suzanne Fleischman Memorial Fund for Patient Advocacy. New donations have been made by:
Edward Fleischman
Precott, AZ
Fay J. Wanetick
Pittsburgh, PA
Roslyn Raney
Mento Park, CA
A memorial fund has been established in the name of Mr. Brian Butterfield

Donations have been made in Mr. Butterfield’s memory by:

- Brooks and Suzanne Ragen
- Seattle, Washington, Kim Ragen
- Fullerton, CA
- Cameron Ragen
- Seattle, WA, Martha Butterfield Wightman
- Tahuya, WA
- Buddy and Lisa Ide
- Minneapolis, MN, Andy and Holly Cohen
- Los Altos, CA
- Lance and Carey Killian
- Portland, OR, Ronald and Lee Ragen
- Portland, OR

A memorial fund has been established in the name of Mr. Lawrence Calvanico

Donations have been made in Mr. Calvanico’s memory by:

- Lawrence & Theresa Calvanico
- Lincoln Park, NJ, Florica Makowski
- Wayne, NJ

A memorial fund has been established in the name of Ms. Maria del Carmen Castillo

Donations have been made in Ms. Castillo’s memory by:

- Gertrudis Achecar
- Dania Beach, FL, Maritza Penzo Achecar
- Dania Beach, FL

A memorial fund has been established in the name of Mr. Lawrence E. Chamberlain

Donations have been made in Mr. Chamberlain’s memory by:

- Joe and Paula Ehmann
- Hunt Valley, MD, Anthony & Dorothy Fumari
- Baltimore, MD
- Sarah Yuhas
- Balto, MD, Robert and
- Bernardine Wittman
- Baltimore, MD
- Roy and Linda Walker
- Forest Hill, MD, Gail M. Hudson
- Baltimore, MD
- Marilyn McMichael
- Liberty Township, OH, Anthony Fumari
- Baltimore, MD

A memorial fund has been established in the name of Ms. Doris Cherkasky

Donations have been made in Ms. Cherkasky’s memory by:

- Debbie Gordon
- Rochester, NY, Jack and Judy Bloch
- Canandaigua, NY
- The Reichl Family
- Palatine, IL

A memorial fund has been established in the name of Mr. Evan Cherkasky

Donations have been made in Mr. Cherkasky’s memory by:

- Ted and Shirley Levy
- Canandaigua, NY

A memorial fund has been established in the name of Mr. Shelton Colson

Donations have been made in Mr. Colson’s memory by:

- Terri S. Sweeney
- Linden, NJ, Stanley and Cheryl Woolard
- Ortonville, MI
- Mark & Robin Muniga
- Livonia, MI

A memorial fund has been established in the name of Ms. Delores Coughennower

Donations have been made in Ms. Coughennower’s memory by:

- Bank of America Matching Gifts
- Charlotte, NC

A memorial fund has been established in the name of Mr. David Crichton, III

Donations have been made in Mr. Crichton’s memory by:

- Jerome Plotner, Esq
- Forest Hills, NY

A memorial fund has been established in the name of Mr. Jesse Crompton

Donations have been made in Mr. Crompton’s memory by:

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- Hampton, VA, Andrew and Doris Byrne
- Hampton, VA
- Women’s Golf Association
- JRCC
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- Alexandria, VA
- Thomas and Lynn Pellegrini
- Avon, CT, Kirk, Shirley, Karen, Lauren
- Hampton, VA
- June Specchio and Family
- Hampton, VA, William and Carol Carpenter
- Deltav Island, SC
- James River Country Club
- Newport News, VA, Arthur & Nancy Henderson
- Newport News, VA

A memorial fund has been established in the name of Mr. Stanley W. Curtis

Donations have been made in Mr. Curtis’ memory by:

- Ed and Judy Laakso
- Newport Beach, SC, Barbara Bettison
- Walla Walla, WA
- Jim and Donna Howard
- Los Osos, CA, Joa D. Jessup
- Murrieta, CA
- Frances Lyon
- Long Beach, CA, Edwin and Shirley Shuff
- Concord, CA
- Rupert and Jane McCook
- Moreno Valley, CA

A memorial fund has been established in the name of Mr. Ian Leslie Denton

Donations have been made in Mr. Denton’s memory by:

- Mrs. M. Appiah-Anane
- United Kingdom
- A.A.C. Brown, Esq., and
- Mrs. Jillian Brown
- United Kingdom
- C. Slater and R. Slater
- United Kingdom
- Mr. D. Raynor
- Bingley, Wrinl, UK
- Quinns of Greasby
- Funeral Service –
- Congregation donations
- United Kingdom
- Mrs. S. Saunders, UK
- U.K.
- C.W. and Mrs. L. Jones
- United Kingdom
- Mr. Geoffrey Denton
- Broughton, Chester, UK
- United Kingdom
- M.P. Bioletti
- United Kingdom
- Mrs. Patricia Denton
- Greasby, Wirral, UK
- Mr. P.E. McAdam
- United Kingdom
- Peter R. and V. McDonald
- Wirral, United Kingdom
- A.A.C. Brown, Esq., and
- Mrs. Jillian Brown
- United Kingdom
- Mr. D. Raynor
- Bingley, Wirral, UK
- Quinns of Greasby
- Funeral Service –
- Congregation donations
- United Kingdom
- Mrs. S. Saunders, UK
- U.K.
- C.W. and Mrs. L. Jones
- United Kingdom
- Mr. Geoffrey Denton
- Broughton, Chester, UK
- Mrs. Patricia Denton
- Greasby, Wirral, UK

A memorial fund has been established in the name of Mr. Edmond Fardella

Donations have been made in Mr. Fardella’s memory by:

- John and Sheila Cilia
- Poughkeepsie, NY, Julie Cilia
- Norma Blundo, Biot, France

A memorial fund has been established in the name of Mr. James H. Farrell

Donations have been made in Mr. Farrell’s memory by:

- Richard and Carolyn Mulkey
- Belmont, MA, Van Sessaohes & Diane Terry
- Lexington, MA

A memorial fund has been established in the name of Dr. Mohammed Abul Fazal

Donations have been made in Dr. Fazal’s memory by:

- Jim and Pat Bergersen
- Oakdale, NY, Lori Spina
- Great River, NY
- Deborah Anzalone
- Central Islip, NY, Stephen & Regina MacAdam
- Rochester, NY

Dr. Mohammed Abul Fazal (continued)

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- Henry and Janet Schreiber
- North Babylon, NY
- Patrick and Nora McGovern
- Deer Park, NY

A memorial fund has been established in the name of Mr. William J. Feely

Donations have been made in Mr. Feely’s memory by:

- Richard and Betty Penner
- Arvada, CO, Bob and Joan Mohar
- Broomfield, CO
- Dan and Darlene Lanham
- Anada, CO, Tom and Sheryl Mohar
- Broomfield, CO
- Mildred, Joan & Ed Lutz
- Golden, CO, Robert and
- Dianne Youkerman
- Arvada, CO
- Fred and Roberta Brethauer
- Anada, CO, Mark and Denise Biren
- Golden, CO

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

Donations have been made in Mr. Foug’s memory by:

- Health Partners Medical Group, Michigan City, IN

A memorial fund has been established in the name of Mr. Sam Friedman

Donations have been made in Mr. Friedman’s memory by:

- William Mark Friedman, Litchfield, CT

A memorial fund has been established in the name of Mr. Kenneth Fye

Donations have been made in Mr. Fye’s memory by:

- R. Junior Fye
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- Grove City, PA
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- Randy and Jane Shaffer
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- David and Debby Fye
- Harrisville, PA, Jean Taylor
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A memorial fund has been established in the name of Mrs. Alyce Gaines
Donations have been made in Mrs. Gaines’ memory by:
- Nick and Argie Klebernas, New Orleans, LA
- Lt. Col. (Ret.) Arthur and Barbara Fournas, New Orleans, LA
- Bill and Robin McConnell, Houston, TX

A memorial fund has been established in the name of Mrs. Jennifer Sharon Gallagher-Welch
Donations have been made in Mrs. Welch’s memory by:
- Sera Edith Gallagher, Dayton, OH
- Lt. Col. (Ret.) Arthur and Nick and Argie Klebernas, New Orleans, LA

A memorial fund has been established in the name of Mr. Theodore M. Gay
Donations have been made in Mr. Gay’s memory by:
- Mark Ferestad and Lisa Bricker, North Bend, OH
- John and Pat Rogers, Heber Springs, AR

A memorial fund has been established in the name of Mr. James Goetz
Donations have been made in Mr. Goetz’ memory by:
- Jill Goetz, Springfield, VA
- Craig Golemieniowicz, McLean, VA

A memorial fund has been established in the name of Mr. Herman E. Gollwitzer
Donations have been made in Mr. Gollwitzer’s memory by:
- James and Bonita Fritsch and Family, Thornton, PA
- Arthur and Barbara Lorenz, Glen Mills, PA

A memorial fund has been established in the name of Mr. Norman Greer
Donations have been made in Mr. Greer’s memory by:
- Jill Goetz, Springfield, VA

A memorial fund has been established in the name of Mr. Melvin Gurell
Donations have been made in Mr. Gurell’s memory by:
- Ted and Shirley Levy, Naples, FL

A memorial fund has been established in the name of Mr. Ralph M. Guzewicz
Donations have been made in Mr. Guzewicz’ memory by:
- Michael Guzewicz, Campbell, CA

A memorial fund has been established in the name of Mr. Martin Heiss
Donations have been made in Mr. Heiss’ memory by:
- Rob and Ellen Busch, East Meadow, NY

A memorial fund has been established in the name of Mr. Andrew Helmich
Donations have been made in Mr. Helmich’s memory by:
- Mike and Vernee Stevenson, Chelsea, MI

A memorial fund has been established in the name of Mr. Luciano Hernandez
Donations have been made in Mr. Hernandez’ memory by:
- Lewis and Natalie Yugel, Northville, MI

A memorial fund has been established in the name of Ms. Mary Howell
Donations have been made in Ms. Howell’s memory by:
- Mariani M. Woodman, Atlanta, GA

A memorial fund has been established in the name of Ms. Luba Jarema
Donations have been made in Ms. Jarema’s memory by:
- The Bresniker Family, Morristown, NJ

A memorial fund has been established in the name of Mr. Allen Kaden
Donations have been made in Mr. Kaden’s memory by:
- Herb and Kay Zales, Melville, NY

A memorial fund has been established in the name of Mr. Steven Kapsaskis
Donations have been made in Mr. Kapsaskis’ memory by:
- Board of Trustees and Staff, Medical Society of New Jersey, Lawrenceville, NJ

A memorial fund has been established in the name of Ms. Dee Karpinski
Donations have been made in Ms. Karpinski’s memory by:
- Sue Marquez, Newark, DE

A memorial fund has been established in the name of Ms. Sharon Kerwin
Donations have been made in Ms. Kerwin’s memory by:
- Veronica Klimas, Philadelphia, PA

A memorial fund has been established in the name of Mrs. Mary Emogene Knight
Donations have been made in Mrs. Knight’s memory by:
- Larson and Dawn Daniel Cameron, AR

A memorial fund has been established in the name of Mrs. Ruth Kolmaister
Donations have been made in Ms. Kolmaister’s memory by:
- Albert J. Kilman, Silver Spring, MD

A memorial fund has been established in the name of Mr. Joseph Kotelnicki
Donations have been made in Mr. Kotelnicki’s memory by:
- Gene Yoshida, Arlington, VA

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Donations have been made in Mrs. Lambert’s memory by:
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Toledo, OH
Honorable Priscilla R. Owen
Austin, TX
Madelyn Koehl, Metair, LA
Col. and Mrs. Ben and Glenda Anderson
New Orleans, LA
Jesse and Mary Cannon
New Orleans, LA
Dr. and Mrs. Earl J. Madere
Gretna, LA
Jay & Jill Nussel, Leo, IV
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Donations have been made in Mr. Lecce’s memory by:
Eugene and Jane Foley, Plano, TX
A memorial fund has been established in the name of Mr. William Ledbetter
Donations have been made in Mr. Ledbetter’s memory by:
Kristin L. Erickson, Reno, NV
A memorial fund has been established in the name of Mr. Edwin C. Lindenberg
Donations have been made in Mr. Lindenberg’s memory by:
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Richard and Judith London
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Carlo and Nancy Vittorini
Bronsville, NY
A memorial fund has been established in the name of Mr. Jerome Grant Lipe
Donations have been made in Mr. Lipe’s memory by:
Charles and Joan Powell
Spartanburg, SC
A memorial fund has been established in the name of Ms. Sheila Lublin
Donations have been made in Ms. Lublin’s memory by:
Ruth Lublin, Bryn Mawr, PA
A memorial fund has been established in the name of Mrs. Gretchen Ludmunity
Donations have been made in Mrs. Ludmunity’s memory by:
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Riverside, CA
Richard and Marilyn Gabriel
Riverside, CA
Michael and Joette Quinn
Riverside, CA
A memorial fund has been established in the name of Mr. Mike Lutzker
Donations have been made in Mr. Lutzker’s memory by:
Stacy Lessing, Milestone Trip., NJ
A memorial fund has been established in the name of Ms. Joan Mangold
Donations have been made in Ms. Mangold’s memory by:
Ann Murawski
Tulsa, OK
Donna Clark
London, Canada
Nick and Dolores Contessa
West Nyack, NY
Skene Epidemiology Center at Boston University
Boston, MA
A memorial fund has been established in the name of Mr. George J. Mattis
Donations have been made in Mr. Mattis’ memory by:
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Jerry and Rita Zacharias
Willow Street, PA
The Woman’s Club of Falls Church, VA
Falls Church, VA
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Donations have been made in Mrs. Matuskevich’s memory by:
Diane Steward
Weatherly, PA
Mr. Paul Prestilliippo and Dr. Jennifer Trella
Wake Forest, NC
Stanley Trella
Wake Forest, NC
Dominic and Congritta LaRegina
Conyngham, PA
A memorial fund has been established in the name of Mr. Paul Maynard
Donations have been made in Mr. Maynard’s memory by:
Kim Hemond and Jay Maynard, Patvuckett, RI
A memorial fund has been established in the name of Mr. Harold Lee Meadow
Donations have been made in Mr. Meadow’s memory by:
Priscilla Joseph, Chicago, IL
A memorial fund has been established in the name of Ms. Monica Meyer
Donations have been made in Ms. Meyer’s memory by:
Don and Geri Baumbatt
Racine, WI
A memorial fund has been established in the name of Mrs. Patricia A. Mitchell
Donations have been made in Mrs. Mitchell’s memory by:
Alvin and Alta Pendleton
Vero Beach, FL
Jewell Laspragota
Vero Beach, FL
Sylvia Garrett
Vero Beach, FL
Lou and Frieda Guillette
Northfield, MA
A memorial fund has been established in the name of Mr. Karl Monahan, Jr.
Donations have been made in Mr. Monahan’s memory by:
Jack and Terri
(Harbor master) Callaghan
Groveland, MA
Daniel, Timothy, Sheila
Chris, and Nancy Howes
Clinton, MA
A memorial fund has been established in the name of Mr. Raymond Morandi
Donations have been made in Mr. Morandi’s memory by:
Bill and Susan Dobbins
New York City, NY
Robert and Catherine Wiescherek
Lancenewater, GA
L. Robert and
Bonnie Haymaker
Egg Harbor Township, NY
A memorial fund has been established in the name of Mrs. Lilian M. Morris
Donations have been made in Mrs. Morris’ memory by:
John W. Morris, Rolling Meadows, IL
A memorial fund has been established in the name of Mr. Victor Nicholas Musmanno
Donations have been made in Mr. Musmanno’s memory by:
Nugent Rudman, East Lansing, MI
A memorial fund has been established in the name of Mr. Robert Knox Newberry
Donations have been made in Mr. Newberry’s memory by:
Ruth Newberry, Salka, AK
Sandra Geize (Canon ITS–SOHO Dept.), Chesapeake, VA
A memorial fund has been established in the name of Ms. Remedios Duculan Nischik
Donations have been made in Ms. Nischik’s memory by:
Jack Nischik, and Judy Johnson
Challisworth, CA
John and Bonnie Miletzlad
Bloomfield Hills, MI
Dearborn Mid-West
Convery Co., Taylor, MI
Meri and Trudy Terry
Auburn Hills, MI
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, Ocean City, NJ
A memorial fund has been established in the name of Ms. Eleanor M. Ogozarek
Donations have been made in Ms. Ogozarek’s memory by:
Dorothy E. Anderson
Philadelphia, PA
Virginia Miller
Chester Springs, PA
Buz and Marge Carter
Cape May, NJ
R. Garvin Berry, Jr., Warren Retirees, Coweta, OK
Bronxville, NY
Riverside, CA
Richard and Marilyn Gabriel
Riverside, CA
Ms. Remedios Duculan Nischik
Riverside, CA
Mr. Raymond Morandi
Plano, TX
Mrs. Gretchen Ludmunity
Riverside, CA
Mr. Mike Lutzker
Stacy Lessing, Milestone Trip., NJ
A memorial fund has been established in the name of Mrs. Bonnie Jean Lambert
Edward and Lorraine Nussel
Honorable Priscilla R. Owen
Madelyn Koehl, Metair, LA
Col. and Mrs. Ben and Glenda Anderson
Jesse and Mary Cannon
Dr. and Mrs. Earl J. Madere
Jay & Jill Nussel, Leo, IV
A memorial fund has been established in the name of Mr. Louis Lecce
Eugene and Jane Foley, Plano, TX
A memorial fund has been established in the name of Mr. William Ledbetter
Kristin L. Erickson, Reno, NV
A memorial fund has been established in the name of Mr. Edwin C. Lindenberg
R. Garvin Berry, Jr., Tulsa, OK
Richard and Judith London
Kenneth K. Steinkirchner – Warren Retirees, Plano, TX
Burl S. Watson, Tulsa, OK
Carlo and Nancy Vittorini
A memorial fund has been established in the name of Ms. Sheila Lublin
Ruth Lublin, Bryn Mawr, PA
A memorial fund has been established in the name of Mrs. Gretchen Ludmunity
Charles and Elaine Ford
Richard and Marilyn Gabriel
Michael and Joette Quinn
A memorial fund has been established in the name of Mr. Mike Lutzker
Stacy Lessing, Milestone Trip., NJ
A memorial fund has been established in the name of Ms. Joan Mangold
Ann Murawski
Donna Clark
Nick and Dolores Contessa
Skene Epidemiology Center at Boston University
A memorial fund has been established in the name of Mr. George J. Mattis
Julie Graves
Jerry and Rita Zacharias
The Woman’s Club of Falls Church, VA
A memorial fund has been established in the name of Mrs. Dorothy Matuskevich
Diane Steward
Mr. Paul Prestilliippo and Dr. Jennifer Trella
Stanley Trella
Dominic and Congritta LaRegina
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Kim Hemond and Jay Maynard, Patvuckett, RI
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Jewell Laspragota
Sylvia Garrett
Lou and Frieda Guillette
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Dr. Samuel & Mrs. Eva Pratt
Ms. Remedios Duculan Nischik
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Edward Nussel
Warren Retirees
Riverside, CA
Richard and Marilyn Gabriel
New Orleans, LA
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Charles and Elaine Ford
Richard and Marilyn Gabriel
Michael and Joette Quinn
A memorial fund has been established in the name of Mr. Mike Lutzker
Stacy Lessing, Milestone Trip., NJ
A memorial fund has been established in the name of

Mr. A. D. Matthews
Donations have been made in Mrs. Matthews’ memory by:

Edward and Janet Haller,
Fergus Falls, MN

Shari Cottet, Valrico, FL

Joanne Adleberg, Baltimore, MD

A memorial fund has been established in the name of

Mr. Harvey Adam Pearlman
Donations have been made in Mr. Pearlman’s memory by:

A memorial fund has been established in the name of

Mr. Bruce A. Schmidt
Donations have been made in Mr. Schmidt’s memory by:

A memorial fund has been established in the name of

Ms. Ethel Schummer
Donations have been made in Ms. Schummer’s memory by:

A memorial fund has been established in the name of

Ms. Beverly Sebastian
Donations have been made in Ms. Sebastian’s memory by:

A memorial fund has been established in the name of

Mr. Donald Sherwood
Donations have been made in Mr. Sherwood’s memory by:

A memorial fund has been established in the name of

Shirley
Donations have been made in Shirley’s memory by:

A memorial fund has been established in the name of

Mr. Paul Robin
Donations have been made in Mr. Robin’s memory by:

A memorial fund has been established in the name of

Mrs. Leticia C. Robles
Donations have been made in Mrs. Robles’ memory by:

A memorial fund has been established in the name of

Mr. Buddy Roberts
Donations have been made in Mr. Roberts’ memory by:

A memorial fund has been established in the name of

Mr. Michael Ostrander
Donations have been made in Mr. Ostrander’s memory by:

A memorial fund has been established in the name of

Ms. Jessie A. Santana
Donations have been made in Ms. Santana’s memory by:

A memorial fund has been established in the name of

Mrs. L. Shaw
Donations have been made in Mrs. Shaw’s memory by:

A memorial fund has been established in the name of

Mrs. Mary Shaw
Donations have been made in Mrs. Shaw’s memory by:

A memorial fund has been established in the name of

Mr. Donnie Sherwood
Donations have been made in Mr. Sherwood’s memory by:

A memorial fund has been established in the name of

Mr. Hal Rosen
Donations have been made in Mr. Hal Rosen’s memory by:

A memorial fund has been established in the name of

Mr. J. R. Round
Donations have been made in Mr. Round’s memory by:

A memorial fund has been established in the name of

Mr. A. D. Matthews,
Worcester, United Kingdom

Donations have been made in Mr. Matthews’ memory by:

A memorial fund has been established in the name of

Mr. Agustín Sierra
Donations have been made in Mr. Sierra’s memory by:

A memorial fund has been established in the name of

Mr. Bob Robinson
Donations have been made in Mr. Robinson’s memory by:

A memorial fund has been established in the name of

Ms. Virginia Stephenson
Donations have been made in Ms. Stephenson’s memory by:

A memorial fund has been established in the name of

Mr. Robert Springer
Donations have been made in Mr. Springer’s memory by:

A memorial fund has been established in the name of

Mr. Mr. Jay R. Southcombe
Donations have been made in Mr. Southcombe’s memory by:

A memorial fund has been established in the name of

Mr. Jack Samson
Donations have been made in Mr. Samson’s memory by:

A memorial fund has been established in the name of

Mrs. Carl and
Lt. Col. Ret. and
Mr. Jack Samson
Donations have been made in Mr. Samson’s memory by:

A memorial fund has been established in the name of

Mr. Walter Schneider
Donations have been made in Mr. Schneider’s memory by:

A memorial fund has been established in the name of

Mr. A. D. Matthews
Donations have been made in Mr. Matthews’ memory by:

A memorial fund has been established in the name of

Mr. Ron Silverstein
Donations have been made in Mr. Silverstein’s memory by:

A memorial fund has been established in the name of

Mr. Neil Smeaton
Donations have been made in Mr. Smeaton’s memory by:

A memorial fund has been established in the name of

Mr. Walter Southcombe
Donations have been made in Mr. Southcombe’s memory by:

A memorial fund has been established in the name of

Ms. Virginia Stephenson
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A memorial fund has been established in the name of

Mr. Charlie Southcombe
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Mr. David Southcombe
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Ms. Jessie A. Santana
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A memorial fund has been established in the name of

Mr. D. J. Round
Donations have been made in Mr. Round’s memory by:

A memorial fund has been established in the name of

Mr. Jack Samson
Donations have been made in Mr. Samson’s memory by:

A memorial fund has been established in the name of

Ms. Virginia Stephenson
Donations have been made in Ms. Stephenson’s memory by:
A memorial fund has been established in the name of Mr. Rocky Sullivan
Donations have been made in Mr. Sullivan’s memory by:
- Iona Sullivan, American Canyon, CA

A memorial fund has been established in the name of Ms. Victoria Suwalski
Donations have been made in Ms. Suwalski’s memory by:
- William and Nancy Suwalski, Peoria, IL

A memorial fund has been established in the name of Mr. Franco Temperino
Donations have been made in Mr. Temperino’s memory by:
- Diane Temperino, Brooklyn, NY

A memorial fund has been established in the name of Mr. Ralph Todino
Donations have been made in Mr. Todino’s memory by:
- George and Carolyn Cross, Pittsburgh, PA

A memorial fund has been established in the name of Mr. Robert E. Totenbier
Donations have been made in Mr. Totenbier’s memory by:
- Harvey and Ruth Holter, Green Valley, AZ
- Don, Lizz and Ross Bellis, Green Valley, AZ

A memorial fund has been established in the name of Mrs. Jeanette Toth
Donations have been made in Mrs. Toth’s memory by:
- David and Donna Bunton, Arlington, VA

A memorial fund has been established in the name of Mr. Art Turley
Donations have been made in Mr. Turley’s memory by:
- Dianne Turley, Maumelle, AR

A memorial fund has been established in the name of Mr. Arnold Tyndall
Donations have been made in Mr. Tyndall’s memory by:
- Serina Kim, Alpharetta, GA
- Fred C. Schmidtke, Wake Forest, NC

A memorial fund has been established in the name of Mr. Richard Valicenti
Donations have been made in Mr. Valicenti’s memory by:
- Victoria V. Michelmore, Port Jefferson, NY

A memorial fund has been established in the name of Mr. Paul M. Vukelic
Donations have been made in Mr. Vukelic’s memory by:
- Joyce Sklocki, Vernon Hills, IL
- Co-workers at OPLL
- Arnold and Kaethe Krause, Buffalo Grove, IL
- Rapeh and Geraldine Spears, Prospect Heights, IL
- UPO LLC, Materials Characterization Group Research Department, Des Plaines, IL

A memorial fund has been established in the name of Mr. Gordon Wascher
Donations have been made in Mr. Wascher’s memory by:
- Bonnie K. Wascher, Saint James City, FL

A memorial fund has been established in the name of Mr. Ralph Robert Webster
Donations have been made in Mr. Webster’s memory by:
- Lou and Linn Polydorius, Surprise, AZ
- Marilyn S. Gunning, Richland, MI
- Chi Chapter, Michigan Alpha Delta Kappa, Plainville, WI
- Charles and Mary Shaw, Richland, MI
- Thomas R. Guerne, South Haven, MI

A memorial fund has been established in the name of Ms. Elaine Wendling
Donations have been made in Ms. Wendling’s memory by:
- Nellie Holt, Holland, MI

A memorial fund has been established in the name of Ms. June Wetzel
Donations have been made in Ms. Wetzel’s memory by:
- Ronald and Zina Staub, McKerrystown, PA
- Tom and Danielle Garber, New Oxford, PA
- Kevin & Elizabeth Klineyoung, Peoria, IL

A memorial fund has been established in the name of Ms. Donna Wiese
Donations have been made in Ms. Wiese’s memory by:
- Jessie Weber, Irvine, CA

A memorial fund has been established in the name of Mr. J.D. Williamson
Donations have been made in Mr. Williamson’s memory by:
- Bob and Shary Johnson, Scottsdale, AZ

A memorial fund has been established in the name of Ms. Ethel S. Wilcoxon
Donations have been made in Ms. Wilcoxon’s memory by:
- Law Offices, Armstrong, Donohue, Coppers & Vaughan Chartered, Rockville, Maryland
- Patrick Sheldon and the NIMH Staff, Hayattsville, MD
- Alma Beck, Toledo, OH
- Linda, Bruce and Burley Macpherson, Bowie, MD
- Gerry and Marla Lynch & Family, Gaithersburg, MD
- Betty Finnegan, Clarksville, MD
- Fred and Betty Wegener, Toledo, OH

A memorial fund has been established in the name of Ms. Ruth Mae Wilson
Donations have been made in Ms. Wilson’s memory by:
- Mark and Eileen Mayes, Newburgh, IN

A memorial fund has been established in the name of Ms. Judith A. Winter
Donations have been made in Ms. Winter’s memory by:
- Jay and Tracey Schwartz, Boca Raton, FL
- Rashmi Benda, Boca Raton, FL
- Jerold and Holly Budney, Boca Raton, FL
- Mitchell and Leslie Greenberg, Boca Raton, FL
- Mitchell Rauch, Boca Raton, FL
- Bruce Freeman, Boca Raton, FL
- Richard and Arlene Court, Boca Raton, FL

A memorial fund has been established in the name of Mr. John S. Wortley
Donations have been made in Mr. Wortley’s memory by:
- Laura S. Wortley, Claremont, CA
- Ted Taylor, White Plains, NY

A memorial fund has been established in the name of Mr. Huei Tong Yang
Donations have been made in Mr. Yang’s memory by:
- Robert Tsai, San Francisco, CA

A memorial fund has been established in the name of Mr. Harold Young
Donations have been made in Mr. Young’s memory by:
- Coleman and Carole Biczak, Rockaway, NJ
- Andy Sachs, Wayne, NJ
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If you would like additional information, please contact us at:
The MDS Foundation
36 Front Street
P. O. Box 353
Crosswicks, NJ 08515
Phone: 800-MDS-0839
Fax: 609-298-0590
Outside the US only: 609-298-1035

Our Website
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The website is constantly being updated to better serve the needs of our patients, their families, and the physicians who treat them.

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