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mds news
newsletter of the myelodysplastic syndromes foundation

The MDS Foundation Moves Forward and Needs Your Help!

SPECIAL ANNOUNCEMENT

The MDS Foundation has moved its headquarters from Crosswicks to Yardville, New Jersey. We are also moving forward with exciting plans to provide services to our patient, caregiver, physician, researcher and nurse communities more effectively and efficiently. Did you know that the MDS Foundation regularly sponsors workshops to help physicians diagnose and treat the disease? Or that the Foundation is sponsoring a project to analyze data from 11,000 patients to aid hematologists and patients in refining their prognoses? Every year the Foundation holds educational symposia for oncology nurses to better equip them to serve MDS patients. Before the end of 2010, the Foundation will reach out with five patient forums in: Detroit, MI; San Antonio, TX; Gainesville, FL; San Francisco, CA; and Durham, NC. In May of 2011, the Foundation will bring together in Edinburgh, Scotland the leading MDS research experts worldwide to compare notes and educate as many as a thousand hematologists on the latest research advances and findings. Meanwhile, at our new office, our Patient Liaison continues to take calls from newly diagnosed patients and their caregivers, refer them to the nearest Center of Excellence and help guide them through confusing periods after diagnosis of the disease. Our website offers patients and caregivers a forum to discuss their questions and concerns with each other. We are also planning a program to establish independent MDS patient groups in countries around the world. These are vitally important tasks aimed at helping patients live with the disease while research continues to search for a way to cure it—or at least develop methods to reduce its symptoms.

However, none of this important work can continue without financial support from the wider MDS community. That is why we are asking you to become a member of the MDS Foundation and, every year, contribute financial assistance to keep us focused on the monumental task at hand. Please also contact us for assistance with tax-advantaged planned gifts, whether during your lifetime or under your estate plans. You can be a vital part of the process by sending your tax-deductible contribution to:

NEW ADDRESS

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

We can be reached from within the US at ***800-MDS-0839*** and from outside the US at 609-298-1035. Our fax number is ***609-298-0590*** and our email address is ***patientliaison@mds-foundation.org***.

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From the Guest Editor's Desk

Iron Overload and Its Management in MDS

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Why is it that MDS Patients Develop Iron Overload?

Patients with MDS accumulate iron by two different mechanisms. On the one hand, iron absorption in the gut is increased because ineffective red blood cell production in the bone marrow generates a long-distance signal which continuously stimulates duodenal mucosa cells to take up more iron than usual. However, the main cause of iron overload in MDS is chronic transfusion therapy. With every unit of packed red blood cells (RBC), the patient receives 200–250 mg of iron. As the normal daily losses, and therefore the normal daily requirement, is only 1–2 mg, a single RBC unit meets the demand of about half a year. Since excess iron cannot be actively excreted, iron overload ensues.

Does it Matter?

Iron is an essential nutrient which is needed for a variety of important cellular functions. So why should it be a disadvantage to have a lot of iron on board? The dictum "Only the dose keeps any substance from being a poison" (Paracelsus) is true of iron as well. Its toxicity in high doses comes from its ability to react with molecular oxygen, transferring electrons to it to create intermediate oxygen species, which in turn, in the presence of iron, cause yet other highly reactive radicals to come into being. These can attack lipids, proteins, and DNA, inducing cellular damage that ultimately becomes clinically manifest as organ dysfunction.

Iron is not dangerous if held in the storage molecule ferritin or bound to the transport protein transferrin. Once the storage and transport capacities of these molecules are exceeded, however, non-transferrin-bound iron (NTBI) begins to appear in the blood plasma. The redox-reactive part of NTBI, known as labile plasma iron (LPI), is rapidly taken up into cells. When the intracellular pool of LPI becomes too large, its effects can no longer be buffered by the cell's antioxidative mechanisms, and the formation of radicals ensues.

Clinical Consequences of Iron Overload

Most of our knowledge of the clinical consequences of iron overload comes from two diseases, namely hereditary hemochromatosis (HH) and thalassemia major. Patients with hereditary hemochromatosis develop iron overload from dysregulated, i.e. permanently increased, iron absorption in the gut. Iron slowly but steadily accumulates in several organs, particularly in the liver, pancreas, and heart, where it causes organ damage that can lead to liver cirrhosis, diabetes mellitus, and cardiac disease. It often takes several decades until the clinical sequelae of HH manifest themselves. The development of complications is more dramatic in patients with thalassemia major who develop iron overload mainly from chronic transfusion therapy starting in early childhood. When iron chelators where not yet available, most patients with thalassemia major died in their second or third decade of life from intractable heart failure, attributable to cardiac iron overload.[1]

One could argue that certain consequences of iron overload, such as hepatic cirrhosis, do not have time to become severe in MDS because patients do not live long enough, due to their bone marrow disease and age-related comorbidities. Indeed, while liver iron content is often greatly increased, full-blown liver cirrhosis is rare in patients with MDS.

What about diabetes? A retrospective analysis in a large US Medicare database showed that diabetes occurred significantly more frequently in MDS patients than in the overall Medicare population,[2] which might be due to transfusional iron overload and/or older age. Unfortunately, the controls were not age-matched. However, the increased frequency of diabetes was only found in MDS patients who received RBC transfusions, not in those who were transfusion-independent, which argues for a role of transfusional iron overload.

What about cardiac problems? Cardiac failure is also more frequent in transfused MDS patients.[2-4] However, besides iron overload, confounding factors like age-related cardiac disease or chronic anemia come into play. Anemia necessitates an increased cardiac output, which puts additional strain on the heart. It is difficult to say to what extent transfusional iron overload is responsible for cardiac problems in patients with MDS. Only a minority of chronically transfused MDS patients have substantial cardiac iron overload as assessed by magnetic resonance imaging. However, there are data from animal studies suggesting that cardiac dysfunction may occur at lower tissue iron concentrations than liver dysfunction.[5] Furthermore, the amount of iron accumulated in the heart may not be the only determinant of iron-related cardiac damage. Repetitive or continuous exposure to labile plasma iron may be another important factor, and the hearts of elderly MDS patients may be particularly vulnerable to this cause of oxidative stress. The relevance of non-transferrin-bound iron is underscored by clinical experience in the field of thalassemia major. Patients with thalassemia who develop cardiac failure can be rescued by intensive chelation therapy before much iron has been removed from the heart. This suggests that substantial clinical benefit can be derived from detoxification of non-transferrin-bound iron.

Besides damage to the liver, heart, and pancreas, other potential consequences of iron overload have recently been emphasized, namely increased susceptibility to infections, accelerated leukemic transformation and increased morbidity and mortality related to allogeneic stem cell transplantation.[6] While it is still speculative that iron-related oxidative stress aggravates genomic instability of bone marrow cells in MDS and thus promotes clonal evolution to AML, an unfavourable impact of iron overload on transplantation outcome is widely acknowledged. Allogeneic stem cell transplantation is associated with disrupted iron recycling. After intensive conditioning chemotherapy, red cell precursors in the bone marrow are lacking for a while. Therefore, large amounts of iron usually taken up by maturing red cells no longer find a recipient. This causes rapid saturation of serum transferrin and appearance of non-transferrin-bound iron.[7] Besides causing oxidative stress, the surplus iron promotes the growth of infectious agents.

Does Iron Overload Compromise the Survival Expectancy of Patients with MDS?

If iron overload is harmful, it should be associated with a decreased likelihood of survival. While this is clearly the case in patients with thalassemia major, it has not been proven beyond doubt in patients with MDS. We know very well that chronic transfusion therapy in MDS is associated with shorter survival.[8] However, this may have several causes. On the one hand, transfusion-dependent patients may develop clinical complications of iron overload. On the other hand, transfusion dependency indicates severe bone marrow disease that may cause complications not related to iron overload. Furthermore, transfusion dependency reflects chronic anemia which can also be detrimental. On multivariate analysis, it has been shown that even after transfusion dependency has been taken into account, iron overload with a serum ferritin above 1000 µg/l remains an independent unfavourable prognostic factor.[9] It might be argued that serum ferritin (SF) is not a reliable indicator of iron overload because it is also influenced by inflammatory conditions. However, by and large, there is a good correlation in MDS patients between ongoing transfusion therapy (causing progressive iron loading) and rising levels of serum ferritin.[10]

Does Iron Chelation Therapy Improve the Survival Expectancy of Patients with MDS?

If iron overload causes clinical complications that decrease the likelihood of survival in MDS, iron chelation therapy should do the opposite. This was indeed first suggested by a small retrospective series from Canada,[11] then corroborated by a larger study from France,[12] and recently underscored by a matched-pair analysis from the Düsseldorf MDS Registry.[13] These studies consistently show that patients with lower-risk MDS who receive iron chelation therapy fare significantly better than those who remain untreated. However, one must be aware of a problem that is common to all these retrospective studies. As the decision to chelate was not randomized, it is impossible to exclude that patients may have been more likely to receive iron chelation if, based on unmeasurable factors, their physicians considered them to have a good prognosis. This potential bias can only be avoided by a prospective randomized placebo-controlled trial. Such a trial is about to start, with 630 MDS patients at 126 centers.

Current Recommendations

Guidelines for the management of iron overload in MDS are currently based on a low level of evidence and usually make inferences from the more established field of thalassemia major. Nevertheless, a number of consensus statements and practice guidelines have been developed by various groups to outline best practice.[14-22] These guidelines vary somewhat in their recommendations for initiating iron chelation therapy and strategies for the ongoing management of iron overload.[23] Overall, they favor starting treatment if more than 20 blood transfusions have been given and serum ferritin levels exceed 1000–2000 ng/ml, recommending serum ferritin levels be maintained below 1000 ng/ml. There is general agreement that the MDS patients most likely to benefit from chelation therapy are those who have a good survival expectancy according to the WHO classification system and the International Prognostic Scoring System (IPSS).

Besides preventing organ damage, iron chelation therapy may achieve improved bone marrow function in a proportion of transfusion-dependent MDS patients. This was clearly seen in a study of intensive treatment with deferoxamine[24] but also observed in some patients (7%) participating in a recent clinical trial with deferasirox.[25] However, such responses seem to be unpredictable.

Most of the previous guidelines recommend deferoxamine (DFO) for iron chelation, while those published more recently also recommend the use of deferasirox (DFX). Clinical trials with MDS patients showed that deferasirox reliably achieves a negative iron balance if the dosage is properly adapted to the intensity of the patient's transfusion regimen. Dosages of 20 to 30 mg/kg/d are usually adequate, but 40 mg/kg/d may be required in heavily transfused patients.[26] It should be noted that deferasirox treatment is less well tolerated in elderly MDS patients when compared with typically young thalassemia patients.[27] Diarrhea is the most common side effect, which can usually be managed by dose reduction but sometimes necessitates discontinuation of the drug. A significant rise in serum creatinine occurs in approximately 25% of MDS patients, but progressive increases can be avoided with appropriate dose reductions. Patients should not be treated with deferasirox if they have a glomerular filtration rate of less than 40 ml/min. With decreasing serum ferritin levels, elevated liver enzymes usually also decrease, suggesting that successful removal of iron by deferasirox leads to

diminished iron toxicity in the liver. However, there have been reports of patients who suffered renal impairment, including failure, hepatic impairment, including failure, or gastrointestinal hemorrhage during treatment with deferasirox. In some reported cases, these reactions were fatal. Therefore, a respective boxed warning was recently placed on the package insert of deferasirox. These reactions were more frequently observed in patients with advanced age, high risk MDS, underlying renal or hepatic impairment or low platelet counts ($<50\times10^9$/L). Deferasirox therapy requires close patient monitoring, including laboratory tests of renal and hepatic function.

Conclusions

Iron chelation therapy has become much easier with the advent of the oral iron chelator deferasirox. To avoid indiscriminate use of the drug, current guidelines should be followed which, admittedly, are not based on rock-solid evidence but reflect the common sense of experienced physicians who took into consideration (1) the toxicity of iron overload, (2) the life expectancy of MDS patients which influences the likelihood of developing iron-related complications, and (3) potential side effects of chelation therapy. To put it in a nutshell, iron chelation therapy (ICT) should be used judiciously: patients most likely to benefit from ICT are those with a good prognosis who yet require regular blood transfusions. One should also consider ICT in patients who have pre-existing cardiac disease that may render them particularly vulnerable to the toxic effects of iron overload. There is also a strong rationale for using ICT in MDS patients undergoing allogeneic stem cell transplantation.[28]

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News From The Foundation

The MDS Foundation Announces Its New Headquarters in Yardville, NJ

The staff of The MDS Foundation (L to R): Nancy Mrzljak, Janice Butchko, Tracey Iraca, Sue Hogan, Deborah Murray, Audrey Hassan.

The Foundation is moving forward with exciting plans to provide services more effectively and efficiently from its new location.

The MDS Foundation
4573 South Broad Street, Suite 150 • Yardville, NJ 08620 USA
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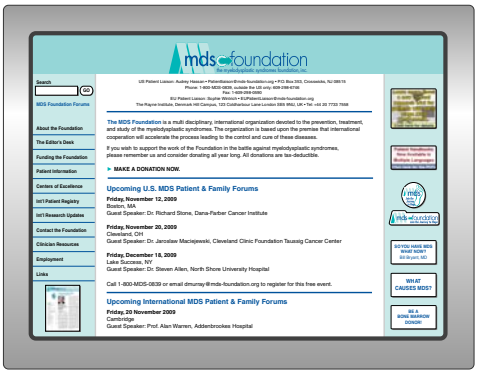
facebook

To find our page on Facebook, type "The MDS Foundation" in the search box located in the top right corner. Once you are there, become a fan to receive updates. Then in the top left corner click the "more" button then "suggest to friends" and send to all your friends.

When the Page is updated with current Foundation information, a notice is sent to all the fans newsfeeds. The Page also allows for Fans to leave comments for others to read or begin a topic in a Discussion Forum.

twitter

Twitter is a free service that lets you keep in touch with people through the exchange of quick, frequent answers to one simple question. Follow us on Twitter at http://twitter.com/MDSFoundation to start receiving the MDS Foundation's tweets.



We hope to see you on the web!

OUR SITE TO SEE!
www.mds-foundation.org

"helping you give hope..."

FOUNDATION INITIATIVES FOR 2010 & BEYOND...

- WORLDWIDE PATIENT QUALITY-OF-LIFE FORUMS
- WORLDWIDE PATIENT SUPPORT GROUPS
- US NURSING ADVISORY BOARDS
- EU NURSING ADVISORY BOARDS

MDS FOUNDATION RESOURCE CENTER

Understanding MDS –
A Primer for Practicing Clinicians
A CME/CE 8-Part Series for Physicians, Nurses, and Pharmacists

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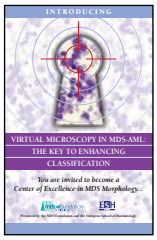

VIRTUAL MICROSCOPY IN MDS-AML: THE KEY TO ENHANCING CLASSIFICATION
A CME Series

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

ADDITIONAL PROGRAMS

- Keys to Identifying Patients at High Risk for Bone Marrow Failure Syndromes: Is it MDS?
- MDS Practice and Treatment Survey available for US and EU Physicians and Nurses
- Patient Questionnaires

INTERNATIONAL WORKING GROUPS

These Working Groups are funded by the Foundation and focus on moving disease knowledge forward by developing essential information through innovative research.

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

THANK YOU TO OUR SPONSORS FOR THEIR SUPPORT THROUGH EDUCATIONAL GRANTS

The Foundation's work is supported by grants from:

Celgene · Eisai · NOVARTIS ONCOLOGY · gsk GlaxoSmithKline Oncology · MSD ONCOLOGY · Centocor Ortho Biotech Inc. · AMGEN

VISIT OUR WEBSITE AND LINK TO OUR EDUCATIONAL RESOURCE CENTER:

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.

mds foundation *Join the Journey to Hope*

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!

mds *Join the Journey to Hope*

Drug News

ANNOUNCEMENT FROM EISAI INC.

FDA Approves Five-Day Dosing Regimen for Dacogen® (decitabine) for Injection, Offering a New Outpatient Dosing Option for Myelodysplastic Syndromes (MDS)

Woodcliff Lake, NJ (March 11, 2010) –

Eisai Inc. announced that the U.S. Food and Drug Administration (FDA) approved a five-day dosing regimen for Dacogen® (decitabine) for Injection to treat patients with myelodysplastic syndromes (MDS), a group of bone marrow diseases that alter the production of functional blood cells.

The new dosing regimen is administered to patients in an outpatient setting with a reduced infusion time compared to the originally approved dosing schedule. The new regimen will be administered at a dose of 20 mg/m^2 continuous intravenous (IV) infusion over one hour repeated daily for five days per cycle. The cycle is repeated every four weeks.

The previously approved Dacogen® three-day regimen is administered in an in-patient setting at a dose of 15 mg/m® continuous IV infusion over three hours repeated every eight hours for three days per cycle and repeated every six weeks.

The approval was gained by the submission to the FDA of three open-label, single-arm, multicenter studies conducted to evaluate the safety and efficacy of Dacogen® in MDS patients with any of the French-American-British (FAB) subtypes. In one study, 99 patients with International Prognostic Scoring System (IPSS) Intermediate-1, Intermediate-2, or high-risk prognostic scores received Dacogen® by IV infusion at a dose of 20 mg/m^2 continuous IV infusion over one hour repeated daily for five days per cycle. The cycle was repeated every four weeks.

If myelosuppression was present, subsequent treatment cycles of Dacogen® were to be delayed until there was a hematologic recovery.

The Dacogen® study results, based on International Working Group 2000 Response Criteria, showed that patients experienced an overall response rate (ORR) of 16 percent (complete remission [CR] of 15 percent and a partial response [PR] of 1 percent). In addition, the median time to (CR+PR) response was 162 days and the median duration of (CR+PR) response was 443 days. These results were consistent with the results of the Phase III controlled trial. The highest incidences of Grade 3 or Grade 4 adverse events in the Dacogen® arm were neutropenia (37%), thrombocytopenia (24%), and anemia (22%).

The two approved dosing regimens of Dacogen® offer doctors and patients the flexibility of choosing the most appropriate dosing regimen for an individual patient.

ANNOUNCEMENT FROM CELGENE CORP.

Celgene Corp (CELG: News): Health Canada Has Approved VIDAZA, an Important Treatment Option for Advanced Forms of a Group of Serious Blood Cancers

Summit, NJ (December 10, 2009) –

According to the company, the pivotal clinical trial, AZA-001 demonstrated that the two-year survival rate almost doubled with VIDAZA treatment compared to conventional care regimens. This data prompted the Joint Oncology Drug Review, the interprovincial body that reviews and makes listing recommendations for cancer drugs, to grant VIDAZA priority review status—only the second such designation to be granted this year.

The company also noted that VIDAZA will be commercially available in Canada in January 2010.

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.

Patient Referrals

Myelodysplastic syndromes can be difficult to diagnose and treat. It is important for both patients and their families to know that optimal treatment is available and that quality of life can be enhanced.

If you would like information about treatment options, research, or quality of life, we would be glad to help. The Foundation offers a variety of patient services, including preferential referrals to the Foundation's MDS Centers of Excellence. We can also help identify physicians and centers to support you if you are travelling and need assistance.

Please contact us at:
1-800-MDS-0839

Outside the US please call:
+44 20 7733 7558

You can visit our website at:
http://www.mds-foundation.org.

The MDS Foundation Says Newly Published Study Finds Vidaza® Prolongs Survival in Acute Myeloid Leukemia

Publication Could Encourage Physicians to Offer Treatment to Patients with this Difficult Cancer

Crosswicks, NJ (February 2, 2010) –

The Myelodysplastic Syndromes (MDS) Foundation says a study published this week in the Journal of Clinical Oncology concludes VIDAZA (azacitidine) "prolongs survival and is well tolerated" in patients with acute myeloid leukemia (AML) — an aggressive form of leukemia that in many cases progresses from MDS. The study looked at older patients with a median age of 70. These are patients who have had "no truly adequate treatments," however the study found that half of the patients treated with VIDAZA survived at least two years, compared to only 16% of patients who received conventional care. Nearly 13,000 AML patients are diagnosed each year in the United States.

"This is encouraging news for patients with AML, an aggressive, difficult to treat cancer where median survival is less than one year," said Kathy Heptinstall, Operating Director of the Myelodysplastic Syndromes Foundation. "Currently, as documented by an editorial in the same journal, a large portion of older AML patients are offered only supportive or palliative care. We would hope that publication of these encouraging results will spread the word and help change the approach to treatment."

The study also found that VIDAZA helped reduce the need for blood transfusions that are often required in AML. 41% of patients on VIDAZA achieved transfusion independence, compared to only 18% receiving conventional care. VIDAZA treatment also significantly reduced the number of days spent in the hospital, and reduced serious infections.

The findings come from a subset of an international study of VIDAZA that previously demonstrated improved survival in patients with higher-risk MDS. Both MDS and AML are malignant conditions of cells in the bone marrow. Previously, the National Comprehensive Cancer Network recommended VIDAZA and DACOGEN® as treatment options for AML patients over 60 years old.

The MDS Foundation Says NICE Decision Against Vidaza® Denies Essential Treatment Option and Denigrates the Value of Patients' Lives

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

Crosswicks, NJ (March 4, 2010) –

The Myelodysplastic Syndromes (MDS) Foundation today issued a statement highly critical of a decision not to make the only drug approved by the European Medicines Agency (EMA) for MDS available to UK patients. MDS is a malignant bone marrow disease with a median survival of less than one year that can also progress to an aggressive form of leukemia called AML. VIDAZA (azacitidine) is crucial to the treatment of this disease, especially for MDS patients over the age of 65 who are not eligible for bone marrow transplants — the majority of MDS patients. Despite this critical need, the National Institute for Health and Clinical Excellence (NICE) in the UK issued a final ruling saying that VIDAZA should not be funded because NICE claims it is not cost-effective.

"This negative appraisal of VIDAZA from NICE denies MDS and AML patients access to the only drug proven to prolong their lives. It is an affront to all patients with haematological malignancies and devalues their very existence," said Kathy Heptinstall, Operating Director of the Myelodysplastic Syndromes Foundation. "In addition to prolonging life, VIDAZA has also been shown to improve the quality of life for MDS patients, many of whom have no other treatment options."

Specifically, the MDS Foundation notes:

- VIDAZA is the only drug available in the UK to significantly extend survival for higher-risk patients with MDS, based on the largest international study in this disease category
- VIDAZA delays progression to AML
- VIDAZA improves quality of life for many patients by eliminating the need for frequent blood transfusions that can themselves lead to serious side effects including iron overload
- VIDAZA is approved and reimbursed in nearly 30 countries worldwide

Cost Issues:

The MDS Foundation also challenged the NICE assertion that VIDAZA is not cost-effective. The foundation says NICE compared VIDAZA to low-cost palliative care and transfusions instead of to chemotherapy which is more expensive, although less tolerable. In so doing, the MDS Foundation believes NICE failed to act fairly in accordance with its own appraisal procedures and violated last year's policy change specifically intended to allow greater access to life-extending medicines. Regardless, the number of MDS patients requiring VIDAZA treatment is small, less than 700 per year in the UK, so VIDAZA would not have a major budget impact.

"We have seen VIDAZA transform patients' lives from a debilitating state to an active, normal life where they can once again be a contributing member to their families and to society," said David Hall, Chairman of the MDS UK Patient Support Group and an MDS patient. "We join the MDS Foundation and a group of patient advocacy organizations in expressing both anger and disappointment in the NICE decision to deny patients the care they so desperately need."

The MDS Foundation and the MDS Patient Support Group will work with both NICE and the drug's manufacturer, Celgene, to appeal and ultimately to attempt to reverse this negative decision.

MDS Young Investigator Grants Program

Young Investigator Grants Award Presentation

The MDS Foundation presented its fifth annual Young Investigator Grants Award Presentation held in conjunction with the American Society of Hematology 51st Annual Meeting and Exposition in New Orleans, Louisiana. The Grant Review Committee headed by Stephen Nimer, MD of Memorial Sloan-Kettering Cancer Center and member of the Foundation's Board of Directors, selected Dr. Andrew Finch's grant submission entitled "The Role of p53 Pathway in the Pathogenesis of Shwachman Diamond Syndrome" and Dr. Ramon Tiu's submission entitled "TET2 Mutations as Marker of Epigenomic Instability in MDS: Therapeutic Implications." As this year's recipients, each will be awarded a $50,000 grant for continued research.

The Young Investigator Grants program was initiated in 2004 to provide assistance to outstanding Young Investigators who are committed to furthering the research into the causes and treatment of MDS.

Andrew John Finch, PhD, University of Cambridge, United Kingdom

Ramon Tiu, MD, Cleveland Clinic Foundation, Cleveland, OH

Sign Up for MDS Essentials E-News

The Foundation has created an 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:

www.mds-foundation.org

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:

THE AMERICAN SOCIETY OF HEMATOLOGY 51ST ANNUAL MEETING & EXHIBITION

Effective Therapeutic Decision Making in MDS: Improving Patient Outcomes and Quality of Life

Ernest N. Morial Convention Center
New Orleans, Louisiana
December 4, 2009

The MDS Foundation held its 12th consecutive satellite symposium on Friday preceding the American Society of Hematology's annual meeting. This symposium, entitled "*Effective Therapeutic Decision Making in MDS: Improving Patient Outcomes and Quality of Life*," was chaired by Dr. John M. Bennett of the University of Rochester in New York.

This program provided participants with the opportunity to not only learn about the most recent changes to the scientific knowledge of MDS but to match their clinical knowledge of MDS with that of a panel of experts in MDS diagnosis, therapy, and quality of life. Accurate diagnosis, stratification of MDS patients, treatment choices, and assessment of therapeutic results (including quality of life issues) provide everyone involved in treating MDS, including this expert panel, with continuous challenges to optimization of outcomes. The expert panel presented a series of 'real life' cases to the attendees coupled with brief scientific updates that may affect the therapeutic choices of the participants. Verbal interaction and electronic decision making allowed for full participation by the audience and provided them with the opportunity for challenging discussions with the experts and other participants regarding options in treatment and the potential effects on patient outcomes.

Ernest N. Morial Convention Center

The topics and international faculty for this symposium included:

- **Evolution in the Prognostic Systems in MDS: What Does that Mean in Terms of Diagnosis and Staging?**
  John M. Bennett, MD
- **Anemia – How Do You Treat It? The Low-risk Patient at Risk for Rapid Progression**
  Moshe Mittelman, MD
- **High-risk MDS: Traditional Treatments and Advanced Therapeutic Options**
  Lewis R. Silverman, MD
- **Issues in Transplant: Early versus Late**
  H. Joachim Deeg, MD
- **What is the Patient's Reality? The View from the Other Side**
  David Cella, PhD

For a copy of the DVD-ROM containing the video and slide presentations from this symposium, please contact the MDS Foundation at 1-800-MDS-0839 or visit our website, www.mds-foundation.org.

The Foundation has participated at ASH for twelve consecutive years by hosting its booth for physician attendees. Our booth is well stocked with all of our MDS educational resource publications including our CME accredited CDs. Physicians from every corner of the globe took advantage of our translated materials and those who treat patients with MDS were surveyed on their practice and treatment practices which will provide crucial information for development of future educational initiatives. (Pictured left to right) Audrey Hassan, Nancy Mrzljak, Sandra Kurtin (MDSF Nursing Advisory Board), Susan Hogan, and Erin Demakos (MDSF Nursing Advisory Board).

MDS Satellite Symposium held at the Oncology Nursing Society (ONS) 35th Annual Congress

San Diego, California
May 13, 2010

Topics for the symposium and faculty speakers included:

AGENDA

- **How Do We Integrate Scientific Information into Our Clinical Practice?**
  Sandra Kurtin, RN, MS, AOCN, ANP-C
- **Strategies for Effective Management of Oral Medications**
  Jean Ridgeway, APN, MSN, NP-C, AOCN
- **Tools for Communicating Emerging Clinical Information to Colleagues and Patients**
  Erin Demakos, RN, CCRC

PROGRAM INFORMATION

The treatment paradigm for Myelodysplastic Syndromes (MDS) has shifted from supportive care to active therapies over the last five years. Scientific advances have provided refined diagnostic capabilities, risk stratification and individualized treatment selection. Supportive care strategies for cytopenias and iron overload remain a challenge. The majority of patients with MDS are elderly with the median age being 70. Integrating recent scientific developments and considering the unique needs of the older adult presents a unique challenge for the oncology nurse. A collaborative approach to managing the elderly adult with MDS is critical to optimal treatment outcomes.

This symposium provided an update on the most recent scientific advances for the diagnosis, management, supportive care, and quality of life for patients with MDS, including selected abstracts from the American Society of Hematology (ASH) annual meeting in December, 2009. Strategies for optimizing oral and injectable therapies for MDS, including reimbursement and financial assistance programs were discussed. Tools for communicating clinical information to colleagues and patients, including patient education tools were presented.

LEARNING OBJECTIVES

- Integrate clinical and translational research into the collaborative management of patients with MDS.
- Identify resources and strategies for management of oral and injectable therapies for MDS, including reimbursement.
- Discuss methods for collaborating with colleagues through case presentations and documentation.
- Utilize available patient education tools to assist patients and families with self-management of MDS.

FACULTY

Erin Demakos, RN, CCRC
Administrative Director
Myelodysplastic Disease Center and
The International Myeloproliferative Disease Clinical Consortium
Mount Sinai Medical Center
New York, New York

Sandy Kurtin, RN, MS, AOCN, ANP-C
Hematology/Oncology Nurse Practitioner
and Clinical Assistant Professor of Medicine
and Clinical Assistant Professor of Nursing
Arizona Cancer Center, University of Arizona
Tucson, Arizona

Jean Ridgeway, APN, MSN, NP-C, AOCN
Adult Hematologic Malignancy
Nurse Practitioner
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University of Chicago Medical Center
Chicago, Illinois

MDS Foundation Patient Liaisons

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mds foundation
the myelodysplastic syndromes foundation, inc.

PLAN TO JOIN US AT

THE 11TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES

EDINBURGH, UK, MAY 18 – 21, 2011

Chairman: David Bowen, UK

CALL FOR ABSTRACTS: FEBRUARY 15, 2011

WWW.KENES.COM/MDS

MDS 2011 Symposium Secretariat c/o Kenes International
1-3 Rue de Chantepoulet, PO Box 1726, CH-1211 Geneva 1, Switzerland
Tel: + 41 22 908 0488; Fax: + 41 22 906 9140; E-mail: mds@kenes.com; © Kenes Group ® 2009. All rights reserved.
For MDS Foundation Contact: US number: 1-800-MDS-0839; Outside the US: 1-609 298-6746

PRACTICE AND TREATMENT SURVEY

The Myelodysplastic Syndromes Foundation would like to know more about your approach to the diagnosis and treatment of patients with MDS.

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 are available.

Please assist us by completing a brief online survey.

Go to **www.mds-foundation.org**

and click on

Physician or Nursing Practice & Treatment Survey

(Surveys are available online in Spanish, Italian, German, and Dutch)

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.

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 backup 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.

UNITED 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: _____

_____

_____

_____

_____

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.

London Patient and Family Forum

London, UK • September 25, 2009

Dr. Kavita Raj, Guy's and St. Thomas' Hospital, London

Professor Mufti, King's College Hospital, London shares the latest advances in MDS research.

Bournemouth Patient and Family Forum

Bournemouth, UK • November 4, 2009

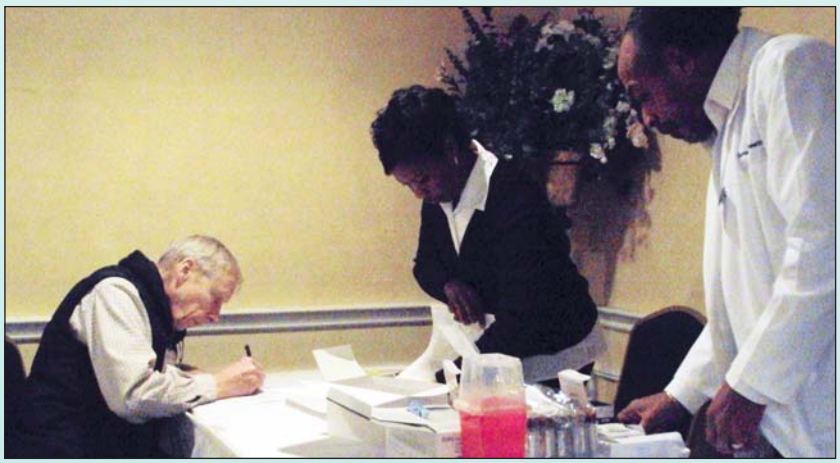
Dr. Sally Killick, Royal Bournemouth Hospital

Long Island Patient and Family Forum

Roslyn, New York • December 18, 2009

Dr. Steven Allen from North Shore University Hospital during his MDS presentation.

Jayshree Shah, Nurse Practitioner at Hackensack University. Hospital and member of the MDSF Nursing Advisory Board [pictured center near microphone] moderates the quality-of-life session with patients and caregivers.



MDS patient prepares to participate in a free serum ferritin screening to check for iron overload.

UNIVERSITY OF PENNSYLVANIA HEALTH SYSTEM

Penn Program for Stress Management

Stressed? Want to learn how to manage your symptoms of stress more effectively? The Penn Program for Stress Management is a mindfulness-based stress management program that uses powerful meditation-based techniques as the primary tool for long-term stress management. Mindfulness is taught as a scientific, systematic approach in which participants learn to rest attention in the moment-to-moment awareness of their experience of physical sensations, thoughts and feelings. Participants of the program thoroughly explore mindfulness and its uses in reducing the symptoms of stress that are experienced in the body and mind. 7 class locations in the Philadelphia region.

To learn more about this program go to www.pennhealth.com/stress or contact:

PENN Program for Stress Management
3930 Chestnut Street
6th floor
Philadelphia, PA 19104

Phone: 215-615-2774
Fax: 215-615-2729
E-mail:
stress.management@uphs.upenn.edu
www.pennhealth.com/stress

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 *(Dec 2004, Oct 2010)*
- Scottsdale, Arizona *(February 2005)*
- Chicago, Illinois *(March 2005, July 2009)*
- Philadelphia, Pennsylvania *(December 2005, February 2006, April 2007, February 2008, July 2009, October 2010)*
- Pittsburgh, Pennsylvania *(February 2006, October 2009)*
- Oak Brook, Illinois *(January 2007)*
- Dallas, Texas *(January 2007)*
- Seattle, Washington *(March 2007, August 2009)*
- Covina, California *(March 2007)*
- Rochester, Minnesota *(June 2007)*
- Baltimore, Maryland *(Sept 2007, June 2009)*
- Rochester, New York *(April 2008)*
- Los Angeles, California *(May 2008, August 2009)*
- Scottsdale, Arizona *(May 2008)*
- San Antonio, Texas *(August 2008, September 2009, August 2010)*
- Atlanta, Georgia *(November 2008)*
- Columbia, South Carolina *(March 2009)*
- Bethesda, Maryland *(August 2009)*
- Birmingham, Alabama *(August 2009)*
- Hackensack, New Jersey *(September 2009)*
- Boston, Massachusetts *(November 2009)*
- Roslyn, New York *(December 2009)*
- Detroit, Michigan *(July 2010)*
- Gainesville, FL *(September 2010)*
- Durham, NC *(November 2010)*

CANADA

- Toronto, Ontario *(October 2009)*

EUROPE

- Edinburgh, UK *(March 2005)*
- Paris, France *(January 2006)*
- Bournemouth, UK *(Feb 2006, Nov 2009)*
- London, UK *(February 2006, September 2008)*
- Hamburg, Germany *(April 2006)*
- Leeds, UK *(May 2006, April 2009)*
- Marseille, France *(May 2006)*
- Vienna, Austria *(July 2006)*
- Prague, Czech Republic *(September 2006)*
- Stockholm, Sweden *(September 2006)*
- Freiburg, Germany *(February 2007)*
- London, UK *(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)*
- Ontario, Canada *(September 2009)*
- Tel Aviv, Israel *(January 2009)*
- Frankfurt, Germany *(March 2009)*
- Stockholm, Sweden *(April 2009)*
- Patras, Greece *(May 2009)*
- Berlin, Germany *(June 2009)*
- Cambridge, UK *(November 2009)*
- Glasgow, UK *(April 2010)*

SOUTH AMERICA

- Buenos Aires, Argentina *(November 2008)*

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.
- Stanford Cancer Center MDS Patient & Family Support Group meets the 3rd Monday of the month, 6:30–8:00 pm at the Stanford Cancer Center, 875 Blake Wilbur Dr., Palo Alto, 2nd Floor Conference Room CC2105. Group Leader: Lenn Fechter, RN, BSN 650-725-0744.

CANADA

- Toronto, Ontario Support Group Contact William Pearson at william.pearson@sympatico.ca or call 905-561-699 for information on upcoming meetings.

JAPAN

- Japanese Support Group Email: mdsrenraku@yahoo.co.jp for more information Website (only in Japanese): http://www.geocities.jp/mdsrenraku

EUROPE *(Countryside Groups)*

- France: Association Connaître et Combattre les Myélodysplasies
- United Kingdom: UK MDS Patient Forum
- Czech Republic: Czech Republic MDS Forum

About the Foundation

Who Are We?

The Myelodysplastic Syndromes Foundation, Inc., was established in 1994 by an international group of physicians and researchers to provide education about MDS to physicians and patients, support for MDS research, patient support, and advocacy.

During the past decade, we have independently solicited funding for ten international symposia that have been attended by over 7,000 individuals—physicians and patients. These symposia are held biannually and have greatly improved our knowledge of these disorders as we continue to provide physicians worldwide with the most up-to-date information on research in MDS. The 10th International Symposium was held in Patras, Greece May 6–9, 2009.

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 in understanding these diseases and the treatment options that are available.

How Can You Help?

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

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

How Can We Help You?

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

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4573 South Broad Street, Suite 150
Yardville, NJ 08620

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Outside the US: 609-298-1035
Fax: 609-298-0590
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123 Coldharbour Lane
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London SE5 9NU, UK

Tel/Fax: +44 20 7733 7558
EUPatientLiaison@mds-foundation.org

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

Visit www.lovinkissesbeading.com.

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.

Women's Journey to Hope Bracelet

Men's Journey to Hope Bracelet

MDS Patients Share Their Stories...

The Foundation would like to invite patients and their families to share their stories with others in the MDS community. Living with MDS poses challenges, and many of you have stories that provide hope to others. Please contact the Foundation, if you would like us to publish your story.

SUBMITTED FROM PITTSBURGH, PENNSYLVANIA

My Story...

Jacqui Konop Buckley

Who imagines their life at the age of 27, newly married, and thinking about babies—to all of a sudden be thinking about cancer and chemotherapy? Certainly not I... but it happened, and it happened quickly.

Here are a few details about myself…

- Diagnosed on June 3, 2009. Found out on June 22, 2009 that I was 6 weeks pregnant. I had to terminate my pregnancy on June 30, 2009 at 7 weeks.
- My bone marrow was 84% packed with leukemic cells (first bone marrow could aspirate nothing). Since it had nowhere else to go, it began to grow from my left leg. After 13 weeks of Revlimid it was down it 7.9%. Another 8 weeks and it was 0!
- Insurance company denied my Revlimid and my case had to go to the Medical Review Board for authorization.
- July 23, 2009 I began Revlimid 25 mg a day no breaks. I was on it for 13 weeks straight, took a week off, and then went back on it for 12 weeks.
- Had to stop working for 5 months. I am a counselor at Western Psychiatric Institute & Clinic (I absolutely LOVE my job!!!).
- I have been hospitalized several times due to severe, debilitating pain. Was on 180 mg of OxyContin and 75 mg of Oxycodone per day along with various other medications.
- Remission February 8, 2010!

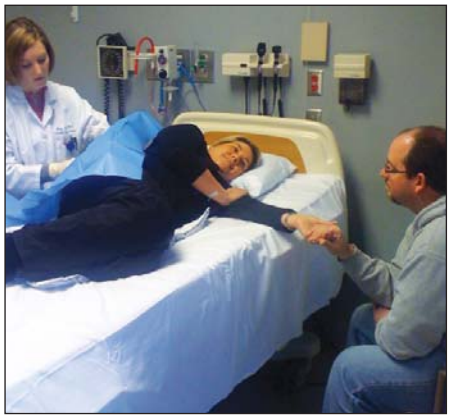
Our wedding – October 4, 2008

Right now...this is my life. I invite you to take a personal look into my life, my diagnosis, my encouragements and discouragements, and the people who support me most!

In April 2009, I was accepted into a research study for weight loss at a local hospital. A surgeon inserted a balloon into my stomach (to keep me full, therefore making weight loss easier). Before the balloon was inserted, I had a full blood workup/health screen/etc. Everything looked fine. I had the balloon in for three weeks. As they were doing routine checkups after the balloon was inserted, they noticed that my WBC (white blood count) was starting to elevate. They watched it closely, and on April 27th they had to take the balloon out because my count was 32,000 (the normal range is between 4,000 and 10,000). They continued to monitor my blood count for another week and then referred me to my PCP. I was not having any symptoms or problems! I went to see my PCP and he took blood to test my WBC again, and this time it was down to 28,000. I was positive that these elevated counts were from the balloon (and I was really angry with myself for even getting that procedure). The doctor said he didn't think that there was any relation between the balloon and the WBC (I still thought he was wrong!). I still wasn't having any symptoms (other than joint pain—which I thought was from the Wii!). Three days later, he checked again, and my WBC had gone up to 38,000, so we knew there was definitely a problem. He referred me to a hematologist at Jefferson Regional Medical Center to get another opinion because he wasn't sure.

I still wasn't having any symptoms (other than joint pain—which I thought was from the Wii!). 3 days later, he checked again, and my WBC had gone up to 38,000, so we knew there was definitely a problem.

I went to the hematologist on June 3, 2009, and he looked at the various blood work results and the blood smear and said that it was leukemia. My mom had gone to the appointment with me and we still had doubts. More tests needed to be done—I should have symptoms, something. He noticed that in previous blood work I had immature cells which signal cancer. He said that it was either Acute Myelogenous Leukemia (AML) or Chronic Myelogenous Leukemia (CML). He told us that if I were going to have one, I should pray that it be the CML because it is easier to treat, fewer symptoms, etc. I went back on June 4, 2009 for a bone marrow biopsy (I was petrified). They gave me some sedation medicine (I was still awake), but it wasn't too bad. It hurt, but not terribly. When I started to cry, the nurse was very nice and held my hand.



Rich comforting me while getting my bone marrow biopsy.

The doctor also explained everything that he was doing, which made it a little easier. The doctor confirmed that in the marrow he saw leukemia (leukemia clumps together making it a gooey white form when the marrow should be red), which made it difficult to get what he needed for the test. They were unable to aspirate anything at all, even after trying three times. My husband Rich and my parents went back with me on Tuesday (June 9, 2009) to discuss the results, course of treatment, etc.

My specific type of cancer ended up coming back as a Dysplastic Leukemia (Myeloproliferative Dx/Myelodysplastic Dx) which is very rare, and there hasn't been much research done on it. A deletion of the Philadelphia chromosome has made it even more difficult (5q-). It was something to hear an oncologist with 20+ years of experience (who even treated my mom!) throw his hands up and say "I've never seen this..." and admit that he has no idea how to even begin to treat my cancer. I was then sent to Hillman Cancer Center where I have the most amazing doctor, Dr. Agha, who will help me fight this battle. He was confident and friendly, and said that he would do whatever he had to do to help us (even promising my parents that if the time comes where I would need a bone marrow transplant, he would find me a match!). I felt comfortable at Hillman and wasn't just a "patient"—I was a person.

Read my journal, share my experiences, be as hopeful as I am!

www.caringbridge.org/visit/jacquibuckley

Mom & I while I was hospitalized in July 2009

SUBMITTED FROM LONDON, UNITED KINGDOM

An Englishman Amongst the Acronyms

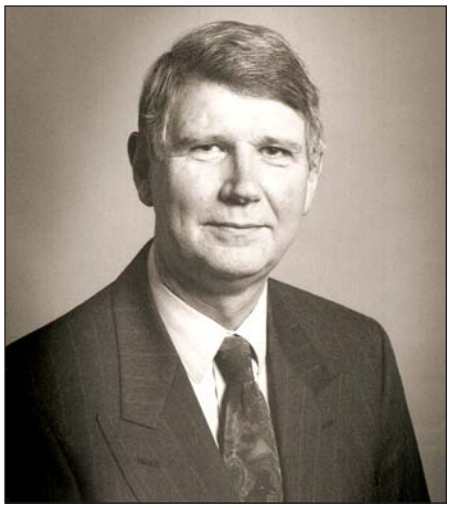
Rodney Taylor
Deputy Chairman
MDS UK Patient Support Group

Each country is different and so are its institutions and its people. But health and disease are much the same wherever you go. The disease process shows up as symptoms or what is described as an illness by the patient who will present eventually to a doctor, be investigated, diagnosed and treated. Or at least that is the way it should be. Some disease processes can develop insidiously with a very gradual onset of symptoms until they are unavoidable and can be ignored no more.

The first indication that anything unusual was going on for me was a blood count done in 1994 which showed that I had a mild neutropenia. I am a hospital doctor and was participating as a 'healthy volunteer' in a colleague's research project. The neutropenia was still present three years later and subsequently, but nothing else was amiss and I felt well with no problems with infection, bruising, breathlessness, tiredness or anything else. I was a busy doctor.

In March 2006 my wife and I went on holiday to Libya. It was a splendid experience visiting the historic sites, travelling widely through the desert, eating a healthy North African diet — and having no alcohol. On our return it seemed a good time to check my cholesterol level, which was fine, but the haematologist picked up signs of MDS in the blood. Red cells, white cells and platelets were all reduced a bit. This led to my referral to Hammersmith Hospital in west London, a nearby postgraduate teaching hospital and centre of expertise in haematology.

Having had excellent health in the past, and feeling well, it was an odd experience being the patient under investigation—I was usually on the other side of the consulting room. I had the usual armful of blood taken



MDS Patient Rodney Talyor

for numerous tests, a bone marrow biopsy, and many other investigations. These confirmed that I had MDS, but there was some disagreement about exactly what type — a discussion which continues. There was however agreement that at that stage I did not need treatment and just needed to have regular monitoring. I was referred to King's College Hospital, a centre of excellence for MDS in south-east London, under the care of Professor Ghulam Mufti.

By late 2008 I was less well, feeling tired and the laboratory measures of blood cells were all beginning to fall. As a physician I was aware of the possible treatment options and some of their implications, though my specialisation is in gastroenterology not haematology. The monitoring became more frequent and as my condition gradually declined, I started GCSF and erythropoietin (EPO) by self-injection. Though these improved the blood counts, I developed worsening bone pain, which can be caused by GCSF, so that was stopped and then EPO was stopped too. I started blood transfusions, usually three units every three weeks, with occasional platelet transfusions when required. Despite this my blood counts continued to decline at a steady rate.

This was when I was started on 5-aza-citidine (Vidaza; AZA). I had a seven day week of subcutaneous injections every month for six months, followed by maintenance treatment with a five day week

of injections each month. This changed the course of my condition and began to restore my wellbeing in a most dramatic way. I felt normal again and could do a full day's work. The only issue now is that the red cell transfusions resulted in iron overload so I now need venesections to reduce my ferritin levels. I can tolerate these without difficulty because my bone marrow is now restored to effective function by AZA.

In the United Kingdom, AZA (I shall call it AZA as we are now on first name terms) is a licensed drug that is not yet recommended for use in the National Health Service (NHS). The body responsible for that is called the National Institute for Health and Clinical Excellence (NICE—the 'H' is silent!). That is a so-called 'arm's length body' from the government that is funded by the Department of Health (DoH). NICE was established because the Government, like all governments worldwide, had finite resources for health, generated by taxation of the people, and needed to control the costs of healthcare. NICE's role is to produce clinical guidelines and to evaluate new healthcare technologies, which includes drugs as well as interventions and diagnostics. In the same way that the NHS is reputedly the envy of the world, NICE is widely respected and its procedures adopted in many other places. In evaluating a drug NICE looks at both its clinical efficacy and, more worryingly, its cost-effectiveness, asking first 'does it work?' and then 'can it be afforded?'.

Not everyone reading this will know how the NHS works, even though it is reputedly the envy of the world as a healthcare system. Although it is nominally a 'national' health service, it is run differently by different bodies in England, where NICE operates; Wales; Scotland, and Northern Ireland, so it is really four health services working to similar principles across the UK. It was established after World War II in 1948 to provide healthcare for all that is provided free of charge at the point of delivery. It is funded by the population through National Insurance (NI) and taxation. It has been a resounding success in providing high quality healthcare to all, irrespective of wealth, background, and influence, responding solely to clinical need. Having spent most of my working career in the NHS, and now as a patient under its care, I have no hesitation in saying that this is the best possible model of healthcare that I have known anywhere in the world.

AZA is now available throughout most of the rest of Europe and North America, but not yet in England. So the 700 or so patients who might benefit from it each year are currently being denied this...

That is, until we come to NICE. I have a great deal of time for NICE's clinical guidelines and much of what it does, but it is slow to respond and there are times when its decisions are not apparently even-handed. AZA has been through this process very slowly for various administrative reasons and NICE finally announced its decision on 4th March 2010 to say that it did not recommend AZA for use in intermediate-2 and high risk MDS, nor in AML or CMML. This was an enormous source of disappointment to the members of MDS UK Patient Support Group. We immediately issued a press release and got widespread media coverage. Much of this is available on the MDS Foundation website as well as our own (http://www.mdspatientsupport.org.uk). We have appealed against NICE's decision and put out another press release to coincide with this appeal. Details of that are also on our website, along with the media coverage. We have now learned that our appeal has been granted and we have been invited to present our case to NICE, backed by full legal support. AZA is now available throughout most of the rest of Europe and North America, but not yet in England. So the 700 or so patients who might benefit from it each year are currently being denied this, the only specific treatment for patients with higher risk MDS. We plan to sort that out.

By the time you read this we shall have had a General Election in the UK on Thursday 6th May. I cannot predict the outcome but it may well be that we have a hung Parliament, that is one with no overall majority. This will make legislation difficult and there may be the possibility of a coalition government for a while. Whatever happens, there is no doubt that health issues are going to be very high on the political agenda, that there are likely to be cuts in real terms to NHS funding for some years to come in the aftermath of the recession, that personal contributions to NHS healthcare through tax and NI will increase, and that an ageing population with rising healthcare needs and costs is going to put increasing demands on the NHS. These are inevitable truths throughout the western world and will remain at the top of the political and financial agendas for generations to come. The science, the technology and the wherewithal to provide top class healthcare are there, but we have to decide whether we can afford it and how to prioritise it. Good quality of life seems to be fundamental but we have to count the cost. AZA has the power to turn lives around dramatically if it is available to those who can benefit from it.

The science, the technology and the wherewithal to provide top class healthcare are there, but we have to decide whether we can afford it and how to prioritise it.

The acronyms abound—NHS, NICE, DoH, AZA, MDS, AML, CMML, GCSF, EPO and more—but what we in the MDS UK Patient Support Group aim to do is to inject some common sense into the discussion to ensure that this enormously valuable treatment is available to all who need it in this country, as it is in so many parts of the world.

Patient Tributes

"Pint for a Pint" Blood Drive

In Honor of Sheldon "Butch" Ginsberg – 200+ Pint Recipient

Rock Bottom Restaurant & Brewery Locations Month of April, 2010

SHELDON'S STORY: LIVING WITH MDS

Sheldon "Butch" Ginsberg is an attorney and an active member of the Denver community. As former Chairman of the Cherry Creek Valley Water and Sanitation District, former Chapter Chairman of the Metro March of Dimes, former Chairman of the Legal Services Committee for the Denver Bar Association, and a Volunteer Attorney of the Year recipient, Sheldon has given hours and hours of his time for people in need.

But lately Sheldon has gone from helping others to relying on the goodness of others for his survival. What Sheldon needs does not come in the form of cash, gifts, or services. It is something only one person can give to another—blood—and Sheldon has needed a lot of blood (approximately 200 pints over the past three years). In fact, Sheldon survives today because a host of anonymous blood donors.

Four years ago, Sheldon was diagnosed with Chronic Lymphocytic Leukemia (CLL). The good news was that, after receiving chemotherapy, he went into remission; however, he remained highly anemic. After multiple tests, Sheldon was diagnosed with Myelodysplastic Syndromes, or MDS. MDS is a bone marrow disorder that affects the ability of one's own body to produce the blood cells necessary for sustaining life. There is no cure for MDS. For many patients suffering from this disorder, regular blood transfusions are the only means to replenish what the body cannot produce. For Sheldon, they have become his lifeline. Nearly three years ago, he required transfusions every six weeks. As the disease has progressed, the transfusions are now required weekly.

Sheldon and Gloria Ginsberg

On a weekly basis, Sheldon spends the day sitting at Kaiser Permanente's infusion center in downtown Denver. Each transfusion takes approximately five hours. The two pints of packed red cells he receives will last him approximately eight days. Then it is back in for the next transfusion; it is a balancing act that never ends. Multiple blood transfusions cause iron overload, a sometimes fatal side effect. Constant monitoring of kidney function, heart function, liver function, and a host of medications must be taken to try to offset the impact to the rest of the body. Without Sheldon's wife, Gloria, who handles all of Sheldon's doctor and nurse appointments and medications, treatment would be nearly impossible to manage.

Even with weekly blood transfusions, Sheldon's blood counts are far from normal. The transfusions only bring up his levels to a fraction of what normal should look like. For the type of MDS Sheldon has, two levels are closely watched: hemoglobin and hematocrit. Hemoglobin carries oxygen from the lungs to the body's tissues and returns carbon dioxide from the tissues to the lungs. A normal range reading for hemoglobin value for a middle-aged male is 12.4–14.9 gm/dl. After a transfusion, Sheldon's "high" normal is 9, well below the normal for people his age.

Hematocrit is the other factor Sheldon's doctors are watching. Hematocrit is the proportion, by volume, of the blood that consists of red blood cells. For an adult male the normal range is 42–54%. A high reading for Sheldon is 25–27%. So, on a good day, Sheldon's hematocrit is roughly half the normal for an adult male.

Think about it… 200+ pints of blood, going to one person. That is why Sheldon's family is so grateful for all of the people who selflessly donate blood. It is those donors who are keeping him alive.

"Pint for Pint" Blood Drive

As a thank you, and to replenish the blood supply in Denver, Sheldon's family–in conjunction with Rock Bottom Restaurant & Brewery–hosted a "Pint for a Pint" replenishment drive during the month of April, 2010. Everyone who donated a pint of blood received a certificate for a free pint of beer from any of the participating 36 Rock Bottom Restaurant & Brewery locations around the country.

For those that cannot donate blood the family is asking for donations to be made in honor of Sheldon to the MDS Foundation.

JOIN Facebook page "Blood Donors are HEROES" at: http://www.facebook.com/pages/Blood-Donors-are-HEROES/332217363830?ref=nf

For more information on this blood drive please contact: Jill Roblyer [jill.roblyer@comcast.net].

REPRINTED FROM *ENVIRONMENTAL NUTRITION*

The Best Catch of the Day: EN's Guide to Eco-friendly, Healthy and Safe Fish

There's a tidal wave of scientific evidence that eating fish regularly is a healthy habit worth adapting. Fish is low in saturated fats and is the main source of the omega-3 fatty acids, eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA). These omega-3 fatty acids have many health benefits, including lowering trigylcerides and blood pressure, slowing the buildup of plaque in the arteries, tamping down inflammation, and reducing the risk of death, heart attack, abnormal heart rhythms and stroke in people with heart disease. No wonder the American Heart Association suggests that you eat fish twice a week. And some research findings indicate that the omega-3 fatty acids found in fish may help reduce joint pain, the symptoms of depression, and protect against Alzheimer's disease. Stretching way back in time, eating fish has been an important part of human health—some scientists believe that our early ancestors relied upon fish as a large part of their diet, which may have supported brain growth.

"Seafood has always been a popular food choice—whether in wealthy nations where it's considered an alternative to beef, pork or chicken, or in poorer nations where it's often the most available and affordable protein source. More recently, researchers have publicized the specific role of fatty acids found in fish in brain health, neurological health and cardiovascular health, and that has made seafood more popular than ever before," explains Brian Halweil, Ph.D., senior researcher at the Worldwatch Institute in Washington, D.C.

Fish has become so popular that the world's fish farmers and fishing fleets harvested 132.5 million tons of seafood in 2003 (the latest year data is available), almost seven times the harvest of 1950.

EN's Fish Guide—Healthier for You, Healthier for the Planet

TOP FISH DOS: *Our top fish picks are ecofriendly, a good source of omega-3 fatty acids, and low in mercury.*

1. Arctic Char
2. Barramundi, U.S. farmed
3. Catfish, U.S.
4. Clams, farmed
5. Cod, Pacific
6. Crab, Dungeness
7. Mussels
8. Oysters, farmed
9. Pollock, Alaska wild
10. Salmon, Alaska wild
11. Sardines, Pacific, U.S.
12. Scallops, Bay, farmed
13. Shrimp, Pink, Oregon
14. Striped Bass, farmed
15. Tilapia, U.S. farmed
16. Trout, Rainbow, U.S. farmed

TOP FISH DON'TS: *The top fish to avoid are guilty of either higher levels of environmental contaminants and/or at least one serious environmental problem such as overfishing or fishing techniques that by-catch other sealife like sea turtles and birds.*

1. Chilean Sea Bass
2. Cod, Atlantic
3. Crab, King
4. Flounder, Sole, Atlantic
5. Grouper
6. Halibut, Atlantic
7. Lobster, spiny, Caribbean
8. Mahi mahi, imported
9. Orange Roughy
10. Rockfish, Pacific (trawled)
11. Salmon, Atlantic, farmed
12. Sharks
13. Shrimp, imported farmed or wild
14. Swordfish, imported
15. Tilefish (Gulf of Mexico/South Atlantic)
16. Tuna, bigeye/yellowfin (imported)
17. Tuna, bluefin
18. Yellowtail, farmed Australia or Japan

Source: Environmental Defense Fund, Seawatch
Note: EN's list does not represent all fish in these categories. Additional recommendations for fish selections can be viewed at EnvironmentalDefenseFund.org.Source: Environmental Defense Fund, Seawatch

Dangerous Waters

Unfortunately, the fish health story gets a bit more complicated. Today's headlines highlight mercury contamination in fish and the dwindling supply of the world's fish populations, prompting people to wonder whether eating fish regularly is such a healthy endeavor after all.

"The world's major fisheries have been taxed for decades. So concern over the sustainability of our fish supply isn't new. It's just that the demands placed on the oceans are greater than ever. The timing is doubly bad because climate change, coastal pollution and other challenges make the oceans less resilient and less productive," stresses Halweil. The Worldwatch Institute reports that roughly twothirds of the world's major stocks have been fished at or beyond their capacity. Another 10 percent have been harvested so heavily that fish populations will take years to recover.

Concerns are also mounting over environmental contaminants showing up in many fish. "Among the major water pollutants that show up in fish and pose a threat to our health, if eaten regularly, is mercury, primarily from atmospheric fallout from coal-fired power plants," says Halweil, who notes that other industrial pollutants, such as polychlorinated biphenyls (PCBs), can contaminate fish as well. To top it off, many modern fishing practices, such as bottom trawling, promote further dangers to the water ecosystem and ocean life.

Navigating Your Way through the Fish Market. The good news is that many varieties of fish are harvested with eco-friendly practices, are not endangered, and have low levels of mercury contamination—making them a wonderful source of omega-3 fatty acids in your diet. Halweil offers the most important tip for finding the best fish choices, "Eat low on the food chain. It's the big, long-lived species like tuna, swordfish, Chilean sea bass and sharks that are most endangered and carry the greatest burden of mercury and other pollutants.

They are popular and they reproduce more slowly than smaller species lower on the food chain, like shellfish, sardines, anchovies and farm-raised fish like carp, catfish and tilapia." Tilapia, one of the most popular fish in America, contains lower levels of omega-3 fatty acids compared with excellent omega-3 sources like salmon, but it can still make a worthwhile contribution to your omega-3 intake goals.

When you're surveying the choices at the seafood counter in the supermarket, it can be difficult to determine which fish are safest for you and the environment. Some of the best food choices may not always seem logical at first glance. For example, farmed catfish shows up on EN's Top Fish Dos, but farmed salmon is on EN's Top Fish Don'ts.

The reason? Some fish are farmed under eco-friendly conditions that reduce exposure to contaminants. Atlantic salmon farms are usually farmed in large-scale, densely stocked netpens that pollute surrounding waters with waste and chemicals.

Take along EN's Fish Guide on your next shopping or dining trip. Organizations like Worldwatch Institute (worldwatch.org), Environmental Defense Fund (edf.org), and Monterey Bay Aquarium's Seafood Watch (montereybayaquarium.org) have also created handy seafood pocket guides that you can carry with you. The Marine Stewardship Council, which certifies some seafood as "sustainable," has approved use of its label for 18 fisheries worldwide, including North Sea herring and Australian mackerel. Over 370 products in almost 30 nations now carry the council's "Fish Forever" logo. Do your best to protect your health, and the health of future fish supplies, by being choosy when it comes to buying fish.

– Sharon Palmer, R.D.

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Food for Thought: Smart Nutrition Tips to Protect the Aging Brain

What's your biggest fear when you consider your golden years? According to surveys, the second most cited fear is the loss of mental function (second only to the threat of cancer). It's a real concern—an estimated 8 million people in the U.S. will suffer from Alzheimer's disease (AD) by the year 2030.

A neurodegenerative disease is a disorder caused by the deterioration of neurons. AD—an irreversible, progressive brain disease that slowly erodes memory and thinking skills—is the most common cause of dementia among older people. The hallmarks of AD are changes in the brain that include neurofibrillary tangles in the entorhinal cortex, amyloid plaques, and the loss of connections between neurons that lead to widespread damage in the brain tissue. The current treatments for this devastating disease have proven to be inadequate at best.

It's only logical that scientists also are exploring the power of nutrition to protect the brain from neurodegenerative disease. After all, we've known for years that certain nutrients, such as omega-3 fatty acids, are essential for normal human brain function.

This is your Brain on Inflammation and Oxidative Stress

In recent years, growing scientific evidence indicates that both inflammation and oxidative stress caused by free radical damage are instrumental in the decline of brain function. "Both oxidative stress and inflammation act to destroy membranes and kill cells so that the brain functions less effectively. As you age, you are less able to deal with oxidative stress and inflammation. You can see an example of this when you look in the mirror and see wrinkles—this is a sign of free radical damage from the sun," says James Joseph, Ph.D., who heads the Neuroscience Laboratory at the Jean Mayer USDA Human Nutrition Research Center on Aging at Tufts University in Boston. Joseph is internationally recognized as a leader in the world of nutrition and brain function research.

Slow, smoldering inflammation is characteristic of all neurodegenerative conditions. According to a 2006 article published in the *American Journal of Clinical Nutrition*, the activation of microglia (tissue macrophages in the central nervous system) in response to injury, illness, aging or other causes begins a cascade of events known as an inflammatory process. Eventually, ongoing inflammation in the brain destroys enough neurons to bring about the telltale signs of AD. Other pro-inflammatory factors, including astrocytes (star-shaped cells in the central nervous system) and tumor necrosis factoralpha (a protein that regulates immune cells) have also been linked to the development of AD.

The effect of oxidative stress on the brain is another critical area catching the eye of researchers. Studies have indicated that oxidative damage to lipids, proteins, DNA and RNA occurs in multiple brain regions in late-stage AD. In addition, AD patients tend to have lower antioxidant status. Antioxidants appear to provide a defense mechanism against oxidation to protect brain function.

Cooling Down Inflammation and Oxidative Stress

"If you can turn down these systems of inflammation and oxidative stress, you're better off.

Every major disease has these two components and it increases as we age," says Joseph.

How can you cool down the inflammation and oxidative stress processes that wreak havoc in the brain? Joseph reports that diet and lifestyle choices can lend a big hand. Numerous studies have indicated that individuals consuming a diet high in fruits and vegetables show fewer age-related diseases like AD. Joseph's research team has published dozens of studies based on wide-ranging research on nutrition and brain function that show that foods high in antioxidants can decrease the enhanced vulnerability to oxidative stress and inflammation that comes with aging.

Joseph's research kicked off with the discovery that rats fed high-antioxidant diets did not experience the age-related cognitive losses seen in rats fed a standard diet. Later, he was able to show reversal of cognitive functional loss among rats fed high-antioxidant diets containing spinach, strawberry or blueberry extracts (with the blueberry-fed group far outperforming the other groups). The blueberry compounds crossed the blood-brain barrier and localized in the rat brain tissues, and the combined antioxidant potency of compounds in the blueberry extract appeared to reduce inflammation in the brain.

Joseph went on to investigate the effects of feeding blueberry extract to mice that carry a genetic mutation for brain plaque commonly seen in AD.

The blueberry-fed mice performed as well as the healthy control mice, and performed much better than the brain-plaqued mice that were fed a standard diet. Most recently, Joseph reported in the *Journal of Nutrition* in 2009 that his research, together with collaborative findings, supported the theory that dietary supplementation with high-antioxidant fruit or vegetable extracts, such as blueberries, strawberries, walnuts and Concord grapes, can decrease oxidative stress and improve cognition in humans with mild cognitive impairment.

Smart Foods for the Brain

You can power up every day on a number of foods linked with brain preservation—here's the short list.

Antioxidant-rich plant foods. "High-antioxidant foods such as berries, nuts and juices contain polyphenols that are also found in red wine, dark chocolate and lots of other foods. They act to block the stress signals to the brain and reduce oxidative stress and inflammation," says Joseph, who stresses the importance of eating a variety of plant foods in a rainbow of colors—yellow/orange, red, green, blue/purple—every day. Fruits, vegetables, nuts, dried fruits, grains, spices, herbs, coffee, tea, cocoa and red wine are rich sources of polyphenol antioxidants.

Omega-3 Fatty Acids. A growing body of research links the brain's principal omega-3 fatty acid, docosahexaenoic acid (DHA), with mental function. Data from several animal studies supports the theory that DHA, found in cold water fish and fish oil, may be an effective treatment for AD because of anti-amyloid, antioxidant and neuroprotectant mechanisms. In addition, plant sources of omega-3 fatty acids, such as walnuts, have been linked with reversing age-related cognitive deficits in rats.

Curcumin. India boasts one of the lowest rates of AD in the world. And researchers from the University of California, Los Angeles are linking curcumin—the principal compound in the popular Indian spice, turmeric—with protection against AD. Curcumin appears to slow the formation of, and possibly even destroy, the accumulated plaque deposits that are at the root of AD. Try including this zesty spice more often in your favorite dishes.

The Mediterranean Diet. You can add lower risk of AD to the long list of health benefits that come along with the Mediterranean diet pattern. Scientists from Columbia University reported that higher adherence to the Mediterranean diet was associated with lower risk for AD—possibly due to reduction in inflammation and an antioxidant effect—in a 2007 issue of the *Archives of Neurology*. "The Mediterranean diet contains good fat like olive oil and nuts and leafy green vegetables. And it's how they cook foods that are important; foods are grilled, not deep-fried," says Joseph.

While the research exploring how foods and nutrients may protect the aging brain is still in its youth, it is clearly pointing in the direction of including smart eating strategies in your diet every week that are health-protective in a number of ways.

— *Sharon Palmer, R.D.*

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EN's Expert Tips for Protecting Your Brain through Lifestyle

Based on his extensive research in nutrition and brain health, James Joseph, Ph.D. shares three key tips for preserving your brain power through lifestyle.

1. Eat Right

That means power up on plenty of antioxidant-rich fruits and vegetables, as well as more fish, whole grains and healthy fats like olive oil and nuts in your diet.

2. Smart Exercise

Include cardiovascular forms of exercise such as walking, jogging or biking, as well as strength training.

3. Work your Brain

Your brain needs exercise to stay young, too. Stay active, maintain social contacts, work your brain with puzzles and try something new to keep your brain from getting complacent.

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The Informed Patient: Where the Germs Lurk — Concern Over Swine Flu Grows, Prompting a Hard Look at the Hygiene Hot Spots During the Day

Laura Landro

They lurk on the kitchen sponge, your computer keyboard and the dirty laundry. Flush the toilet and they become airborne. Strangers leave them behind on airplanes, gas pumps, shopping carts, coffeeshop counters and elevator buttons. Your desktop, office microwave handles, and the exercise bike at the gym are covered with them. Don't even think about the toys at day-care centers or the kids' playground equipment.

Germs — the microscopic bacteria, viruses, fungi and protozoa that can cause disease — cling to the most common surfaces and then hitch a ride on our hands. As swine flu spreads from person to person around the world, it is most often being transmitted by coughing or sneezing, but it can also infect people who touch something with flu virus on it and then touch their mouth or nose, the Centers for Disease Control and Prevention warns. And like an unwelcome house guest, a flu virus can hang around for days.

No wonder germophobes—including me—are on high alert, viewing every surface as a potentially lethal petri dish. We're using our elbows to push elevator buttons, forgoing the handshake and social kiss for the fist bump, and fanatically disinfecting everything in sight. Sales of alcohol-based hand sanitizers were up nearly 17% as of the first week of September compared to the same period last year, according to Chicago-based research firm Information Resources. And marketers are taking full advantage of our paranoia, introducing anti-bacterial dishwasher-safe keyboards, machine-washable leather shoes, germ-resistant paper file folders and even hands-free communion wafer dispensers for churches.

But how vulnerable are we to the sea of germs swirling around us? Our immune system protects us from most of them, and in some spots that harbor germs, like household drains, the risk of transfer is low. Experts say there's no reason to panic — even though there may be good reasons to be grossed out, since the spread of germs is often linked to poor bathroom hygiene and bacteria from human waste.

"We take in humongous amounts of live organisms every day, and we are all routinely covered in fecal organisms," says Michael Bell, associate director for infection control at the Centers for Disease Control and Prevention's Division of Healthcare Quality Promotion. "It's a testament to our body's own defenses — if they routinely made us ill, none of us would have a chance."

Even the scariest bugs can usually be vanquished through old-fashioned hand washing. "Regardless of what you touch, make sure you clean your hands on a regular basis so you have a better chance of not delivering bacteria into your body through your mouth, nose and eyes or a cut on your skin," Dr. Bell says. He advises thorough and frequent hand cleaning — which may be needed 10 times or more daily depending on your activities — with soap or alcohol-based hand sanitizer.

Cleaning and disinfecting things like desks and doorknobs can play a role in protecting us, he says, but "focusing on one surface misses the point, because no surface is not germy." (The CDC.gov Web site offers information on keeping germs at bay in the home, how to wash your hands correctly, and the importance of flu vaccines and other immunizations in preventing disease.)

Also, not all germs are harmful; we need friendly bacteria that live on our skin to help fight off bad bugs, and bacteria in our mouth and gut help digest our food and prevent illness and disease.

Still, I wanted to know where in my home, office and wider world I should most forcefully brandish my disinfectant wipes and hand-sanitizer. My calls to experts turned up some surprising culprits: the public toilet seats I'd always been warned about are likely cleaner than the desks in my workplace. My kitchen sponge and cutting board harbor the biggest dangers, as do places like elevator buttons, communal coffee carafes and gym equipment, that are touched by many hands and are rarely cleaned.

"We are sharing more surfaces than ever before in history, spending more time indoors, travelling on bigger planes and cruise ships and working in bigger office complexes," says Charles Gerba, a microbiologist at the University of Arizona's Department of Soil, Water and Environmental Science. "The biggest risks are in areas of high contact — like the hundreds of people who have touched that escalator rail before you did."

One of the scariest germ incubators may be the office. Your co-worker eating at the next cubicle isn't just annoying you with the smell of fried onions — he's leaving behind particles of food that can be breeding ground for bacteria. Add in the microbes transferred from workers' hands to keyboards, phones and the computer mouse, and the average office desk may harbor 400 times more germs than the average toilet seat, since office desks and surfaces may be rarely cleaned, while bathrooms tend to be disinfected regularly, Dr. Gerba says.

After testing surfaces and objects in 113 offices in five cities, the Arizona researchers found that women's offices had more than twice the bacteria of their male counterparts. Makeup cases, phones and purses had the highest number of bacteria; for men it was wallets, hand-held electronic devices and phones. Women's offices had higher numbers of mold and yeast, mostly from food kept in drawers. But the superbug MRSA, isolated in 6% of offices, was found more often in men's offices on the phone, computer mouse, desktop and the bottom of desk drawers.

The studies are funded by makers of disinfectants including Procter & Gamble and Clorox, whose products were also used to test the effectiveness of cleaning and compare regular cleaning regimens to disinfecting with substances like bleach. Dr. Gerba says more research is needed on the link between surface germs and disease, since it's impossible to say who will get sick.

"Some people will never get ill no matter what they do or don't do, and others will get ill almost every time," he notes.

At home, the kitchen may be the germiest room. About 50% to 80% of food-borne illnesses happen in the home, where micro-organisms can be spread from raw meat and vegetables on chopping boards, utensils and counters, and then spread on hands. The culprits are dangerous bacteria such as *E. coli*, *salmonella* and *campylobacter*. They cause food-borne illnesses that strike 76 million people each year, sending 300,000 of them to the hospital and killing 5,000.

One problem is haphazard cleaning; a study by the U.K.-based Hygiene Council found that in 12% of cases, surfaces that looked clean in homes were heavily contaminated. Sponges and cleaning cloths can be swarming with bacteria from previous wipe-ups, so to be on the safe side, it's best to use paper towels, disposable cloths or reusable ones that have been decontaminated and dried, the group advises. The CDC advises microwaving sponges for 30 seconds or putting them in the dishwasher every other day or so depending on how often you use them.

In the laundry room, your average load of wash contains more than coffee stains. The Hygiene Council also warns it can be packed with bacteria such as *E. coli* from clothing, towels and linens. Washing in cold water doesn't kill the germs; if you have to wash at lower temperatures, add a laundry disinfectant. Wash your hands after loading the washing machine and dry clothes immediately, since bacteria and fungi build up on damp items, the group advises.

In the bathroom, the family toothbrush holder can also harbor bacteria; if you have to all share the same one, don't allow the brushes to touch each other, the CDC recommends. But it also says there is no evidence to support disinfecting toothbrushes in the microwave or with ultraviolet devices on the market. Best strategy: Get a new one every few months and rinse thoroughly after using.

And keep your toothbrush away from the commode—especially the powerful flush of toilets on airplanes. Some studies have shown that flushing sends a spray of water containing bacteria that settles on people and surrounding surfaces.

In general, fecal particles are only worrisome if they've come from someone with intestinal illness or diarrhea, but the best advice I ever heard was to treat all airplane bathroom surfaces as if they are radioactive; keep the lid closed when flushing, use a paper towel to handle lid, faucets and door handles after washing hands, then use hand sanitizer once back at the seat as an extra precaution.

While surfaces are often the leading source of germs, remember germs can thrive in water we may inadvertently swallow at public swimming pools (don't ever get in one if you see a baby without a swim diaper) and waterparks (think of all those people who may not be diligent about personal hygiene). Hotel hot tubs can be bubbling cauldrons of rash-causing *Pseudomonas aeruginosa*, as chlorine and other disinfectants evaporate more quickly in high temperatures. And communal showers may harbor foot fungus.

After reviewing all this depressing information, I turned to my own doctor, New York infectious disease specialist Eric Neibart, who helped bring me down to earth — sort of. What are the chances of picking up an infectious disease from the germs we come in contact with daily?

"Millions of people touch things every day and nothing happens, so just use common sense," Dr. Neibart advises. "There's a bigger risk of being injured in a taxicab."

Email: informedpatient@wsj.com

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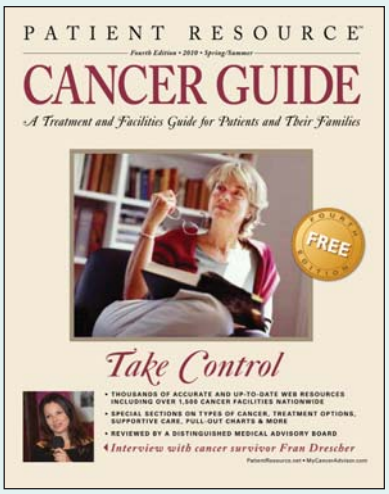

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mds centers of excellence

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

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

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

The following centers have qualified as MDS Centers of Excellence:

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Birmingham, Alabama
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Mayo Clinic Hospital
Phoenix, Arizona
Ruben A. Mesa, MD/James L. Slack, MD

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Gregory Hale, MD

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Jacksonville, Florida
Alvaro Moreno-Aspitia, MD

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

University of South Florida H. Lee Moffitt Cancer Center and Research Institute
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The Blood and Marrow Transplant Program at Northside Hospital
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Asad Bashey, MD

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Maywood, Illinois
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NEBRASKA

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

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Balkis Meddeb, MD

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

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Suzanne Fleischman Memorial Fund for Patient Advocacy

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

New donations have been made by:

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Jaroslav Cermák, MD, PhD

Welcome Additions to MDS Centers of Excellence

The MDS Foundation is pleased to announce the following additions to our Centers of Excellence program in MDS:

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New York, New York
Azra Raza, MD

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

National Taiwan University Hospital
Taipei, Taiwan
Hwei-Fang Tien, MD, PhD

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

University Hospital of Wales
Cardiff, UK
Jonathan Kell, MD

Seoul National University Hospital Seoul National University College of Medicine
Seoul, Korea
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Odense University Hospital The University of Southern Denmark
Odense, Denmark
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Copenhagen, Denmark
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Information on Clinical Trials

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.cancer.gov. This information includes basic study information, study lead organizations, study sites, and contact information. To access the information:

- Log on to www.cancer.gov
- Click on "Search for Clinical Trials"
- Click on "Type of Cancer" and type in 'myelodysplastic syndromes'
- Hit search

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

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

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 study new interventions (drugs or procedures) to evaluate their safety and effectiveness in humans. Trials follow a careful set of steps, allowing for the systematic gathering of information to answer questions and confirm hypotheses that were formed earlier, in either laboratory experiments or preliminary trials.

A clinical trial falls into one of four phases:

Phase I. This is the first time a drug is used in humans. The trial is designed to determine dosage, route of administration (oral, intravenous, or by injection), and schedule of administration (how many times a day or week). In this phase researchers also begin to determine the drug's safety. The phase I trial is normally conducted in healthy adults and enrolls only a small number of people.

Phase II. Patients with the disease receive the drug at dose levels determined in the earlier phase. The phase II trial begins to determine the effectiveness of the drug and provides more information about its safety.

Phase III. The drug is tested alone or against an approved standard drug. The typical phase III trial enrolls a large number of patients. If it is a comparison trial, patients may be randomly assigned to receive either the new drug or the standard intervention.

Phase IV. In phase IV the drug, already approved by the FDA and available to the public, undergoes continued evaluation. The phase IV designation is rare.

Some trials—screening studies evaluating supportive care or prevention—are not conducted in phases. In these trials a group following a certain disease combating strategy, such as a detection method, is compared to a control group.

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:
uspatientliaison@mds-foundation.org

or call 800-MDS-0839 and the current clinical trials will be sent to you.

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

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

Clinical Research Trial with Eltrombopag – Now Open for Accrual

PMA112509

We would like to announce a clinical trial for patients with advanced Myelodysplastic Syndrome (MDS) or secondary Acute Myeloid Leukemia after MDS (sAML/MDS), or de novo AML who have associated thrombocytopenia (low platelet counts).

The Myelodysplastic Syndromes Foundation is assisting in the accrual of patients for **Clinical Trial PMA112509**. The purpose of this phase I/II placebo-controlled study is to test the safety of eltrombopag in patients with low platelet counts due to MDS, sAML/MDS, or de novo AML, and also to see how well eltrombopag may work at different doses in this patient population.

Eltrombopag is an orally available, small molecule thrombopoietin receptor agonist that is approved as a treatment for chronic immune (idiopathic) thrombocytopenic purpura (ITP) to increase platelet counts. The present study is designed to evaluate the safety and tolerability of eltrombopag, administered as oral tablets once daily in adult thrombocytopenic subjects with advanced MDS, sAML/MDS, or de novo AML.

In an effort to move the clinical development of eltrombopag for the treatment of MDS, sAML/MDS, or de novo AML forward as rapidly as possible, the Foundation would appreciate hearing from you.

If you are a physician and would like to refer a patient for enrollment into this clinical trial *or* if you are an MDS patient who has low platelet counts, please contact The MDS Foundation at 1-800-MDS-0839.

Online Search Tool for Clinical Trials

TrialCheck® | Clinical trials information and products powered by: Coalition of Cancer Cooperative Groups

TrialCheck is another online search tool that helps you gather information about cancer clinical trials to discuss with your doctor. This user-friendly tool allows you to search for trials according to your type of cancer and according to your zip code. This will help you locate physicians and hospitals near your home that offer trials.

TrialCheck searching is based on nine simple questions. Depending upon the answers you provide, TrialCheck generates a list of trials in which you may be eligible to enroll.

www.CancerTrialsHelp.org

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

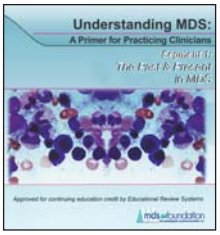
Bone Marrow and Cord Blood Transplantation:
http://bloodcell.transplant.hrsa.gov

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.

Educational Resources

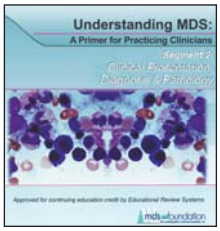
Understanding MDS: A Primer for Practicing Clinicians

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.



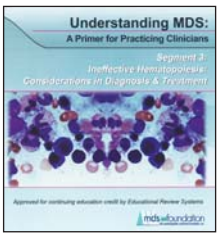
Segment 1 – *The Past & Present in MDS*

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.



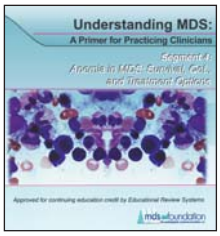
Segment 2 – *Clinical Presentation, Diagnosis & Pathology*

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.



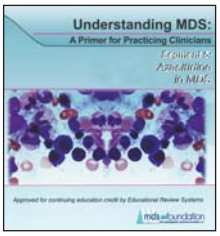
Segment 3 – *Ineffective Hematopoiesis: Considerations in Diagnosis & Treatment*

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.



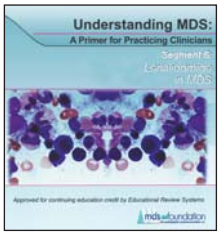
Segment 4 – *Anemia in MDS: Survival, QoL, & Treatment Options*

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 – *Azacitidine in MDS*

Segment 5 looks at the mechanism of action of the MDS treatment, azacitidine and patient selection criteria for use. The labeled and licensed indications as well as associated risks of azacitidine are reviewed.



Segment 6 – *Lenalidomide in MDS*

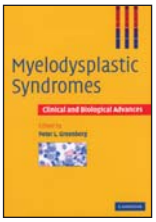
Segment 6 looks at the mechanism of action of the MDS treatment, lenalidomide and patient selection criteria for use. An overview of the labeled and licensed indications as well as associated risks is reviewed.

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.

Help the Foundation and Buy Your MDS Textbooks From Us!



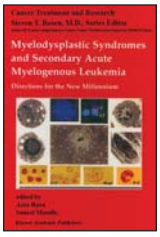
Myelodysplastic Syndromes: Clinical and Biological Advances

Peter L. Greenberg, MD
Stanford University Medical Center

Hardback, Nov. 2005/320 pp., illus.
ISBN: 0521496683/$168.00**
Cambridge University Press

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.

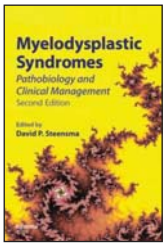
This book will be a valuable resource to clinicians and researchers who wish to learn more about myelodysplastic syndromes.



Myelodysplastic Syndromes & Secondary Acute Myelogenous Leukemia: Directions for the New Millennium (Cancer Treatment and Research)

Edited by:
Azra Raza, MD; Suneel D. Mundle, PhD
June 2001/278 pp., illus.
ISBN: 0792373660/$228.00**
Springer Press

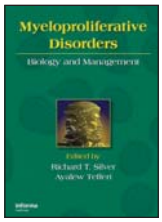
Myelodysplastic syndromes are to the bone marrow what pneumonia is to the lungs: the response of an organ to a variety of etiologic insults like aging, toxic exposure, infections and auto-immunity. Among infectious causes alone, pneumonia could be the result of a variety of possible pathogens including 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 (Basic and Clinical Oncology)

Edited by:
David P. Steensma, MD
November 2008/536 pp., illus.
ISBN: 978-01420074390/$250.00**
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

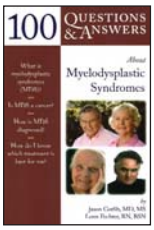
Edited by:
Richard T. Silver, MD; Ayalew Tefferi, MD

October 2007/240 pp., illus.
ISBN: 9781420061628/$200.00**
Informa HealthCare

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 cytogenetics on understanding these diseases

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:
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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.

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Highlights of Latest Literature in MDS

Suneel D. Mundle, PhD

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

EPIDEMIOLOGY:

1. Goldberg SL et al. Incidence and clinical complications of Myelodysplastic Syndromes among United States medicare beneficiaries. *J Clin Oncol*. 2010;Apr 26 [Epub ahead of print].

   The incidence of newly diagnosed MDS patients registered during 2003 in Medicare Standard Analytic Files with age ≥65 yr was 162 per 100,000 cases, which may yield a value of 45,000 new cases a year in the US medicare population 65 yr or older. The study also showed higher incidence of comorbidities in patients requiring RBC transfusions. Additionally, the transfusion status correlated with higher rate of leukemic transformation and high rates of mortality.

2. Ehsan A and Aziz M. Clinico-haematological characteristics in Pakistani patients of primary myelodysplastic syndrome according to world health organization classification. *J Coll Physicians Surg Pak*. 2010;20(4):232-236.

   A small study that is in line with earlier observation of younger mean age of MDS at diagnosis in Asia as compared to the advanced age of western patients. Forty-six patients evaluated had mean age of 46.21 yr, higher preponderance of disease among males and a high incidence of RCMD class.

3. Dayyani et al. Cause of death in patients with lower-risk myelodysplastic syndrome. *Cancer*. 2010;116(9):2174-2179.

   This retrospective single center study of 273 deceased cases with low-risk MDS recorded cause of death in 84% cases as MDS-related death (38% as a result of infection, 15% due to transformation into AML, 13% hemorrhage and the rest were labeled as disease progression or others).

DIAGNOSIS AND PROGNOSIS:

1. Costa et al. Do we need to do fluorescence in situ hybridization analysis in myelodysplastic syndromes as often as we do? *Leuk Res*. 2010;Mar 10 [Epub ahead of print].

   Fish studies confirmed the findings of conventional G-banding cytogenetics in 99.4% cases and detected abnormalities in additional 25% cases in which the latter had failed. No value was seen in conducting FISH in cases with normal cytogenetics.

2. Yang W et al. FISH analysis in addition to G-band karyotyping: utility in evaluation of myelodysplastic syndromes? *Leuk Res*. 2010;34(4):420-425.

   Upon evaluation of a series of 110 MDS patients, this report concluded that FISH may be informative only in cases with failure of conventional karyotyping and would have marginal utility in cases where G-banding conclusively demonstrated normal karyotype.

TREATMENT:

Growth Factor:

1. Oliva EN et al. Darbepoetin alfa for the treatment of anemia associated with myelodysplastic syndromes: efficacy and quality of life. *Leuk Lymphoma*. 2010;Apr 6 [Epub ahead of print].

   Forty one patients were treated with a dose of 150 µg/week (increased to 300 µg/week in non-responsive cases). Response rates in transfusion dependent patients were 59% and in non-transfusion dependent cases were 56% with increase of 1 g in the mean Hb levels during 24 weeks of treatment. Duration of response was 22 weeks in non transfusion dependent and 15.1 weeks in transfusion dependent cases.

Demethylating Agents:

1. Moon JH et al. Predictive value of pretreatment risk group and baseline LDH levels in MDS patients receiving azacitidine treatment. *Ann Hematol*. 2010; Mar 17 [Epub ahead of print].

   This retrospective study over a window of 2 years, 2006–2008, assessed outcomes of azacitidine treatment of 126 MDS patients. The study compared median survival in different IPSS and WPSS classes. Markedly WPSS high/very high risk category showed higher OS as compared to IPSS high risk category (14.9 mo vs. 6.3 mo respectively). Also, high LDH levels were found to be correlated with poor prognosis (OS–13.9 mo in high vs. 20.6 mo in normal).

2. Musto P et al. Azacitidine for the treatment of lower risk myelodysplastic syndromes: a retrospective study of 74 patients enrolled in an Italian named patient program. *Cancer*. 2010;116(6): 1485-1494.

   The study focused on efficacy and safety of azacitidine in lower-risk patients, 84% of whom were transfusion dependent at baseline. Azacitidine was administered at a dose of 75 mg/m^2 qd with majority receiving 5 or 7 day regimens. A third of the patients were treated at a fixed dose of 100 mg daily on similar regimens. Treatment continued for a median of 7 cycles. Per IWG 2006 criteria, ORR–45.9% (CR–10.8%, PR–9.5%, HI–20.3%). The ORR was higher in patients completing ≥4 cycles (51.6%). Median DOR 6 mo with survival benefit seen in responders as compared to non-responders. Major Gr 3/4 AE-myelosuppression and infection.

PATHOBIOLOGY:

1. Steensma DP et al. P39/Tsugane cells are a false cell line contaminated with HL-60 cells and are not suitable for mechanistic studies in myelodysplastic syndromes. *Haematologica*. 2010;Apr 26 [Epub ahead of print].

   This letter reviews the contamination status and cautions against the use of P39/Tsugane cells in future.

2. Zheng Z et al. In Vitro deprivation of CD8+CD57+ T-cells promotes the malignant growth of bone marrow colony cells in patients with lower-risk myelodysplastic syndrome. *Exp Hematol*. 2010;Apr 12 [Epub ahead of print].

   This study reported on the presence of intact immune surveillance element, i.e. CD8+CD57+ cells that demonstrate inhibitory activity against MDS bone marrow mononuclear cells, but not against those derived from normal marrows. Of note, the inhibitory activity was more pronounced against cytogenetically abnormal cells.

3. Pellagatti A et al. Deregulated gene expression pathways in myelodysplastic syndrome hematopoietic stem cells. *Leukemia*. 2010;24(4):756-764

   This study conducted global gene profiling in 183 MDS patients and 17 healthy controls. The study highlights deregulation of distinct molecular pathways correlating with different cytogenetic abnormalities. Trisomy 8 had deregulation in immune response pathway, –7/del 7q showed involvement of cell survival pathways, whereas del 5q showed derailment of integrin pathways and cell cycle regulation.

4. Lange K et al. Telomere shortening and chromosomal instability in myelodysplastic syndromes. *Genes Chromosomes Cancer*. 2010;49(3):260-269.

   In line with earlier data, the authors have reported telomere shortening in MDS. Additionally, the report also showed that normal and aberrant metaphases from the same patient had no difference in telomeric length, indicating the disease origin in a very early stem cell.

NOTE:

Special Journal issue on MDS

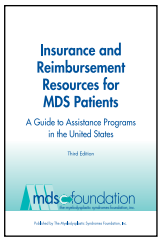
1. *Hematol Oncol Clin North Am.* 2010;24(2)

   Review articles on diagnosis, prognosis including WHO, IPSS and WPSS system evaluations, existing and new treatments, iron overload, and, biology, cytogenetics and genomics of MDS, etc.

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.

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.

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
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New from the MDS Foundation...

- It Takes Time to Realize Your Goals
- What Does My Bone Marrow Do?

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
- Planned Giving Program: A Guide to Financial Planning

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

Thank You!

Gifts to the Foundation

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

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In memory of Dr. Jerome Ferber
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A Special Thank You to

GABRIELLE'S ANGEL FOUNDATION FOR CANCER RESEARCH

We would like to especially thank *Gabrielle's Angel Foundation for Cancer Research* for their generous grant in the amount of $45,000.00 in support of young investigators through the MDS Foundation.

Ways to Support the Foundation's Work All Year Long

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

Every penny helps. All donations are tax-deductible.

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

Thank you for your support.

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Frederick and Laura Bone
Raleigh, NC

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Rocky Mount, NC

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Charles and Barbara Kaeho, *Lindenhurst, NY*

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Robert and Connie Nold
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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:

Bill and Liz Kindred

This donation was submitted by:

Marcella Couturiaux
West Islip, NY

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Membership Information

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

Membership benefits include issues of the MDS News, a special subscription rate of $119.00 for Leukemia Research (a substantial discount from the current institutional subscription rate of $2,373), and the worldwide Centers of Excellence patient referral service.

If you would like additional information, please contact us at:

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Phone: 800-MDS-0839
Fax: 609-298-0590

Outside the US only:
609-298-1035

Our Website

The MDS Foundation website is for healthcare professionals, patients, and other interested people. The Professional Forum and the Patient Forum are integral parts of our website.

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

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

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