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THE MDS NEWS

The Newsletter of The Myelodysplastic Syndromes Foundation

From the Guest Editor's Desk

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THE CHALLENGE OF MYELODYSPLASIA

The myelodysplastic syndromes [MDS] are a heterogeneous group of disorders ranging the gamut from patients with moderate anemia with normal neutrophil and platelet counts to others with essentially frank leukemia. Clinical courses can range from a few months to many years and it is clear that a number of biologically distinct disorders are combined under this rubric, awaiting further molecular characterization to allow better classification. MDS may be the most common hematopoietic neoplasm in adults and appears to be rising in incidence, in part because of the aging of the population in the Western world. It is probably underdiagnosed and may be the cause of some of the mild to moderate anemia encountered in older people which is attributed to "chronic disease."

Because of the availability of some new approaches to treatments, there has been increased interest in the problems posed by MDS on the part of clinicians, laboratory scientists and funding agencies. Pharmaceutical companies and the horde of investment analysts who trail one step behind have also recognized that there is a considerable potential market for an effective treatment given to lots of patients over a long period of time. On a positive note, this has resulted in an increase in the number of clinical trials. However, there has also been an increase in the amount of preliminary, sometimes incomplete information from a variety of sources, which is often confusing and potentially misleading for patients and physicians.

Unfortunately, there are very few randomized trials comparing active treatment with what was, until at least recently, the standard of supportive care. Most reports are Phase I/II trials with relatively small numbers of patients with heterogeneous clinical characteristics. In addition, the number of abstracts far exceeds the number of peer reviewed publications, with drug company symposia and "consulting" meetings becoming an increasing source of information transmission. In particular, "negative" experiences are likely underrepresented in presentations at national meetings and in the literature. It is thus sometimes difficult for patients and physicians to assess the true response rates or side effect profiles of particular therapies.

(continued on page 2)

Contents

Some Things We Would Like to Know About the Biology of MDS

MDS is a clonal disorder affecting the hematopoietic stem cell. It is generally resistant to standard anti-leukemia chemotherapy with lower complete response rates and shorter durations of response than in "de novo" AML. In addition, there is often a prolonged period of cytopenia following chemotherapy due to delayed recovery of normal hematopoiesis, a distinct problem in the elderly population of patients with MDS. This suggests a deficiency in either the quality or number of residual normal stem cells. Although there has been a recent increase in laboratory studies focused on the fundamental biology of MDS, we know relatively little about the molecular disturbances resulting in such a profound disruption of blood cell production. Specifically:

– The mechanism(s) by which the development and proliferation of a dysplastic clone suppresses the growth of residual normal hematopoietic elements is not understood. Although the increase in apoptotic cell death in patients with hypercellular MDS is associated with increases in "inflammatory" cytokines and angiogenesis, it is not clear whether these are primary pathogenic events and hence "targetable" therapeutically, or whether they are simply reactive.

– It is also unknown whether recovery of peripheral blood counts following successful therapy for MDS is attributable to the return of polyclonal hematopoiesis or reflects improved differentiation capacity of the MDS clone.

– There is little information about the self-renewing malignant stem cell in different subtypes of MDS. In vitro studies of whole marrow cell populations may be less informative than studies of separated progenitors and many groups are focusing on CD34+ separated cells in an attempt to study immature precursors closer to the elusive MDS stem cell.

– There is no animal model representative of any of the subtypes of MDS, necessitating that most drug trials are empiric in nature with doses and schedules selected with less in vitro background than in many other cancers.

– Gene expression studies in MDS are in their infancy

Problems in Interpreting the Results of Clinical Trials

Comparisons amongst reports of treatment outcome had been hampered by the inclusion of heterogeneous groups of patients with different expected clinical courses and an absence of agreed upon definitions of response. Thus, it is quite possible that some apparently "positive" results were more a consequence of patient selection and liberal definitions of response then a major effect of the treatment. These issues have been addressed by a number of international committees in recent years. The IPSS categorization has certainly helped to standardize the prognostic characteristics of the patients treated on a given trial.[1] It remains to be seen however, whether the WHO morphologic classification[2] adds appreciably to the older FAB description. Response definitions have also been more rigorously defined, although it will require prospective studies to confirm the clinical relevance of some of the "softer" definitions of hematologic improvement.[3] The universal use of these criteria should produce more consistency in the literature. Importantly, however, none of these classification efforts provide important biological insights or new clues about directions for innovative therapies.

Treatment

A wide variety of compounds such as glucocorticosteroids, anabolic steroids, pentoxyllophyline, amifostine, TNFα inhibitors and most recently arsenic trioxide, hypomethylating agents (5-azacytidine and decitabine) and thalidomide (and its analogue, lenalidomide, Revlimid™) have been used to treat MDS; hematologic improvement has been demonstrated in a fraction, generally <20%–30%, of patients. A few generalizations can be made:

– The hematologic responses seen are infrequently "complete", occur more often in lower risk IPSS subgroups, are usually not multilineage, generally are manifested by decreases in RBC transfusion requirements and infrequently last for more than 6–12 months. An exception may be the sometimes sustained responses seen (perhaps most commonly in patients with hypocellular MDS) following immunosuppressive therapy with anti-thymocyte globulin.

– Virtually all therapies are accompanied by systemic side effects, some of which are significant. These include transient or sustained worsening of cytopenias with a need for hospitalization and increased transfusion requirements. Treatment may also be associated with appreciable additional costs, some of which, such as travel for physician visits and blood counts, are often underestimated. This can be a major burden, especially for older patients.

– Treatment with most agents must be given for many weeks to months before responses are apparent or treatment failure can be declared. Treating physicians must be aware of this, so that therapy is not discontinued prematurely, and it is important that the need for this sustained "commitment" be discussed in detail with the patient before therapy is started.

– Most protocols exclude individuals with significant medical co-morbidities that are quite common in older patients with MDS. It is quite possible and indeed likely, that overall results will be inferior in patients with poor performance status. There is also no systematic information about the large number of patients who are treated on an ad hoc basis off clinical trials or who elect not to receive treatment.

The Treatment Decision

Whether to Treat

Despite these caveats, there is little doubt that responding patients can enjoy major clinical benefit from effective therapies. Conversely, non-responding patients can have non-responding major decrements in their quality-of-life and perhaps, shortening of survival. Thus, the decision about how and whether to treat individual older patients must balance the potential side effects and the low frequency of response against the severity of the current and projected symptoms which the patient is experiencing. Additional considerations include the short- and intermediate-term prognosis, which can be *roughly* assessed by the IPSS score, the presence or absence of recent changes in the pace or manifestations of the disease, as well as unique social issues and goals in particular patients. Indeed, considerable "art" still remains in medical decision-making and it is advisable to seek opinions from physicians with ongoing experience with MDS.

And With What?

The fragmentary nature of much of the data makes it difficult to know whether the available results are predictive of the outcome in patients with specific subtypes of MDS, a critical issue, given the wide variation in clinical behavior amongst the "syndromes". Currently, 5-azacytidine is the only FDA-approved treatment for MDS and, in the absence of available clinical trials of new agents, should be an initial consideration for most patients.[4] Although the drug was approved for all FAB types, in reality, there were relatively few patients in the different morphologic and cytogenetic subtypes in the "pivotal" trial. While the overall long-term results are disappointing (median survival ~19 months in the 99 patients initially randomized to 5-azacytidine), some patients did derive substantial clinical benefit. Both 5-azacytidine and decitabine are cytotoxic when given in higher doses but have other mechanisms of action, including DNA demethylation, which can enhance the expression of epigenetically "silenced" genes, which when activated may help promote malignant cell death. It remains to be proven however, that the induction of specific gene expression is in fact responsible for any clinical response.

Unfortunately, there is little information suggesting a preferential effect of other treatments in different subtypes, with the *possible* exceptions of the high response rates reported in preliminary form with lenalidomode (Revlimid™) in patients with the 5q-cytogenetic abnormality[5] and the results of immunosuppressive therapy in patients with hypercellular marrows and possibly those of HLA-DR15 histocompatibility antigen type.[6,7] There are no data about the response rate following other types of therapy in patients with hypocellular MDS and not all published experience with anti-thymocyte globulin is positive.[8] Two large multi-institutional Phase II trials with lenalidomode (Revlimid™), which focused on patients with lower risk MDS or the 5q- syndrome have recently been completed. The mechanism for the apparent disproportionately good effect in the 5q- patients is not known.

AML-type induction therapy needs to be considered in suitable patients with increasing numbers of blasts and associated cytopenias despite the lower response rates and allogeneic stem cell transplantation is suitable in younger patients with higher IPSS scores and progressive disease.[9] High relapse rates remain a problem after "full" allogeneic transplantation for MDS and it is not clear whether reduced-intensity regimens which are being explored in older patients will be associated with even higher rates of relapse.

Summary

Given the paucity of alternative treatments, the decision about off-protocol use of a commercially available agent can be difficult, further complicated by the dearth of complete, peer-reviewed publications and randomized trials. Certainly, patients should be referred for exploratory trials if available and fortunately, a number of protocols are available in research institutions. Most trials in MDS have been based on modest preclinical data and have been largely empiric in nature, with some post hoc rationales offered to explain successes or failures. It is therefore also difficult to design trials of rational combinations of agents. It is hoped that better understanding of the biology(ies) of these heterogeneous disorders will provide more hypothesis driven approaches in the near future which will further improve outcome.

Thank You to Our Pharmaceutical Partners

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

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Share Your Stories With The MDS Community

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!!!

PBS Presents

A new series on PBS, ***Healthy Body, Healthy Mind***, offers a segment devoted to MDS and the MDS Foundation. Please check your local listing for this special segment of this new series.

The Foundation offers its special thanks for Celgene's support of a new health and wellness TV series, ***Healthy Body, Healthy Mind***.

For a VHS copy of a 30-minute documentary style program of **"MDS"** call 1-800-MDS-0839.

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

MDS Foundation Charity Golf Tournament

The MDS Foundation held it's Inaugural Charity Golf Tournament on Monday, August 9th, 2004 at Olde York Country Club (OYCC) in Chesterfield, NJ. The Gary Player signature course welcomed a full field of golfers on this beautiful summer morning. After breakfast was served, the golfers enjoyed an hour-long golf clinic hosted by our guest of honor, top-ranked Senior PGA Professional, Bruce Fleischer. Bruce was the winner of the 2001 U.S. Senior Open. He reviewed the fundamentals, and the mental side of golf and swapped tour stories with the audience and his former caddie Jack. The 11:30 AM shotgun start sent everyone to their respective holes to begin a Texas scramble format golf game. Bruce was stationed on Hole #11, 180 yard par 3, where, after taking a photo with each foursome, he played the hole with each group. Once again, the field of players demonstrated to Bruce that no two golf swings are alike.

Dinner and a cocktail reception were held after the tournament. Dr. John Bennett gave a short talk on MDS, the symptoms of the disease, who it affects, and how important it is to raise money to continue the research in this field.

The MDS Foundation would like to express our gratitude for the generous support given by Celgene, Pharmion, Apotex, Cell Therapeutics and Telik. The Foundation is dedicated to improving the quality of care and resources provided to our patients. The money raised through this tournament will further research efforts, with the hope of some day finding a cure for this disease.

We hope everyone enjoyed the Inaugural MDS Foundation Charity Golf Tournament and will reserve the date of August 1st, 2005 for next year's tournament.

Bruce Fleischer prepares to hit the ball on the green at this Par 3, 180 yard hole at OYCC in Chesterfield NJ, during the MDS Foundation's Inaugural Charity Golf Tournament.

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8th International Symposium on Myelodysplastic Syndromes

May 12–15, 2005

Nagasaki, Japan

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- Classification and diagnosis
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Second announcement and call for papers:
October 2004

Deadline for abstract submission:
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For further information please contact:
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Abstract and Registration Forms are available from the MDS website:
http://www.mds-foundation.org

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.

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

University Tor Vergata
Ospedale S. Eugenio
Roma, Italy
Sergio Amadori, MD

University of Vienna
Vienna, Austria
Peter Valent, MD

MDS Walk-A-Thon Held

Special Thanks to the Ingle Family

The family of MDS patient, Lois Ingle, is one of many thousands of families living with the reality of MDS. They have come up with an extraordinary way to contribute to the MDS Foundation and support our mission of working as a resource for patients, families, and healthcare professionals.

On October 2, 2004 Beth Ingle and her family held an MDS Walk-A-Thon at Kellogg Forest in Augusta, Michigan on behalf of their mother who was diagnosed with MDS three months ago. The Ingle family along with their friends raised over $1300.00 to benefit research for MDS. Lois Ingle is currently being treated with Vidaza™ and is doing well. Our thanks to this family for their tremendous effort!

Donations on behalf of Lois Ingle were submitted by:

Beth Ingle, *Rockford, IL*
Richard and Lois Ingle, *Battle Creek, MI*
Michael and Julie Ingle, *Battle Creek, MI*
Don and Sandra Ingle, *Lake Wales, FL*
Dan and Rhonda Madden, *Battle Creek, MI*
Michelle Wooden, *Delton, MI*
R.J. and Michel Mullenix, *Battle Creek, MI*
Lawrence and Reva Zeno, *Battle Creek, MI*
Peg Case, *Battle Creek, MI*
Monica Thacker-Duncan, *Battle Creek, MI*
Marjorie Kiessling, *Marshall, MI*
Bernice Peck, *Battle Creek, MI*
Kathy Whitesell, *Battle Creek, MI*
Robert and Janet Damon, *Battle Creek, MI*
Durrel and Deanne Stults, *Battle Creek, MI*
Keith and Julie Sutton, *Battle Creek, MI*
Robert and Margaret Cunningham, *Battle Creek, MI*
Maxine Phillips, *Battle Creek, MI*
Jerome and Kari Crane, *Pecatonica, IL*
Doni and Jan Bain, *Battle Creek, MI*
Judy Stone, *Battle Creek, MI*
Pauline Bicksford, *Battle Creek, MI*
Bob and Nancy Brownlee, *Battle Creek, MI*
Keith Walback, *Battle Creek, MI*
Fran Hubbard, *Battle Creek, MI*
Bruce Rohrer, *Battle Creek, MI*
Shelia Loston, *Battle Creek, MI*
Tracy Sprague, *Battle Creek, MI*
Wendy Boettger, *Kalamazoo, MI*
Rev. and Mrs. Cary Grant, *Battle Creek, MI*
Jeff O'Brien, *Plainwell, MI*
Joanne Lewis, *Battle Creek, MI*
Heather White, *Battle Creek, MI*
Beth Rea, *Battle Creek, MI*
Sandra Martin, *Battle Creek, MI*
Penelope A. Blake, *Roscoe, IL*
Carole Cotter, *Rockford, IL*
Steven and Mariann Waite, *Galesburg, MI*

MDS Patient Registry

The patient registry form has been revised and a patient authorization form has been developed to meet the new HIPAA guidelines. The Patient Registry will help further research into the etiology, diagnosis and treatment of MDS. Currently, the MDS Patient Registry is only accepting patients through our designated Centers of Excellence. A two page data sheet will be forwarded to investigators who wish to contribute patient's names to the Registry. The Registry is located at the MDS Foundation's Statistical Center at the University of Rochester Cancer Center. The Foundation looks forward to building the Patient Registry with our Centers of Excellence. If you would like to become a Center of Excellence, please contact The Foundation at the address below.

The MDS Foundation
PO Box 353
Crosswicks, NJ 08515

Phone: 1-800-MDS-0839 within the US
Outside the US only:
1-609-298-6746
Fax: 1-609-298-0590

MDS Foundation Plans 2005 Initiatives

The MDS Foundation is committed to making a significant contribution to the advancement in understanding and of accurately diagnosing the myelodysplastic syndromes. We will be focusing our efforts in the following initiatives for the upcoming year:

- **CME Awareness Program**
- **MDS Foundation Charity Golf Tournament August 1, 2005**
  Supported by grants from:
  Celgene Innovating Life™ · PHARMION · Pfizer · cti Making cancer more treatable™ · APOTEX INC. Canadian Pharmaceutical Company · TELIK Innovating for life · genzyme
- **MDS Practice and Treatment Registry**
- **The International Morphology Working Group**
- **MDS Patient's Quality-of-Life Forums**
- **Transfusion Burden Initiative**
  Supported by a grant from: Celgene Innovating Life™
- **Patient Sero-Therapy Registry**
  Supported by a grant from: genzyme

Patients: Your Help is Needed!

We would like to invite you to participate in selected study groups and share your experience living with MDS and the quality-of-life issues that you face. The information we develop will be used to educate healthcare professionals about MDS patients' needs in dealing with these diseases. The number of groups and their location will depend upon the responses we receive. Please join us in this most important endeavor. Further developments will be posted on our website or for more information contact Audrey Hassan our Patient Liaison at 1-800-MDS-0839.

MDS

About the Foundation

The Myelodysplastic Syndromes Foundation was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS.

Until the Foundation was set up, no formal working group had been devoted to MDS. During the past decade we have conducted seven international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, and France. The Eighth International Symposium is being held May 12–15, 2005 in Nagasaki, Japan.

A major Foundation effort is our international information network. This network provides patients with referrals to Centers of Excellence, contact names for available clinical trials, sharing of new research and treatment options between physicians, and extension of educational support to both physicians and patients.

In response to the needs expressed by patients, families, and physicians, we have established patient advocacy groups, research funding, and physician education.

The MDS Foundation is a publicly supported organization, exempt from federal income tax under section 501(C)(3) of the IRS code.

Our Website

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

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

We welcome your suggestions.

Please visit us at *http://www.mds-foundation.org*

International Clinical Trials: An Update

The following trials are current as of the date of this newsletter. We will update the list in The MDS News each quarter. If you are a treating physician who would benefit from any such study, you may want to contact the appropriate institution. 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.

U.S. Trials

NATIONAL CANCER INSTITUTE TRIALS*

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

- Log on to www.nci.nih.gov
- Click on "Finding Clinical Trials"
- on the next screen look for "Ways to Find Clinical Trials" and
- Click on "Search for Clinical Trials"
- Click on "Type of Cancer" and type in 'myelodysplastic syndromes'
- Hit search

This search will provide you with all the trials currently underway in MDS. You may also sort by trials that only focus on treatment or trials that only focus on supportive care. You can also contact 1-800-4-CANCER for more information.

ADVANCED CANCERS: A NEW TRANSPLANT METHOD

Researchers at the National Institutes of Health (NIH/DHHS) are investigating a new method of improving transplant results in individuals with advanced cancers. If you or someone you know are between the ages of 10 to 50 years old and have one of the following cancers: Myelodysplastic Syndrome, Leukemia, or Myeloproliferative Disorder, you may be able to participate in this clinical trial. To find out if you qualify, please call 1-800-411-1222 or visit www.cc.nih.gov.

Novartis. Phase I, open-label, dose escalating study to evaluate the safety, biologic activity and pharmacokinetic profile of LAQ824 in patients with relapsed or refractory AML, CLL, or CML in blast crisis, or advanced MDS. The primary objective of this study is to determine the Maximum Tolerated Dose (MTD) and Dose Limiting Toxicity (DLT) of LAQ824 as a single agent when administered by intravenous infusion as outlined in the protocol.

An Open-label Phase II Trial of PKC412 Monotherapy in Patients with Acute Myeloid Leukemia and Patients with Myelodysplastic Syndrome PKC4122104. Patients who agree to participate in this trial will be screened for the FLT3 mutation. If positive, they will have a physical exam, blood test, EKG, chest x-ray, bone marrow aspirate and a pregnancy test.

Phase II, open-label trial evaluating the safety and efficacy of deferasirox for treatment of transfusional iron overload in adult patients with myelodysplastic syndromes. Planned to start February 2005.

Pharmion. AZA PH GL 2003 CL 001. A Survival Study in Patients with High Risk Myelodysplastic Syndromes Comparing Azacitidine versus Conventional Care. The purpose of this study is to determine whether patients with high-risk myelodysplastic syndromes (MDS) treated with azacitidine have improved survival compared to conventional care treatments. The study will also assess the effect of treatments on response, duration of response, and transformation to acute myeloid leukemia (AML).

Telik, Inc. Phase I-IIa trial to evaluate the safety and efficacy of TLK199 in patients with myelodysplastic syndrome (MDS). Eligible patients must have a diagnosis of MDS, be at least 18 years old and ineligible or refusing bone marrow transplant.

For more information, please go to www.clinicaltrials.gov.

Other U.S. Trials

Barbara Ann Karmanos Cancer Institute, Detroit, MI. D-696. Allogenic and syngenieic marrow transplantation in patients with acute non-lymphocytic leukemia. Contact: Jared Klein, MD. Phone: 313-963-2533.

Barbara Ann Karmanos Cancer Institute, Detroit, MI. POG A2971: Treatment of Children with Down Syndrome and Acute Myeloid Leukemia, Myelodysplastic Syndrome, or Transient Myeloproliferative Disorder. Contact: Jeffrey Taub, MD. Phone: 313-963-2533.

Cancer and Blood Institute of the Desert, Rancho Mirage, CA. Phase I/II study of arsenic trioxide in combination with cytosine arabinoside in patients with MDS. Contact: R. Lemon. Phone: 760-568-4461.

Cancer Institute Medical Group, Los Angeles, CA. Phase I/IIa Study of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes. Contact: Lawrence D. Piro, MD. Phone: 310-231-2182.

Case Western Reserve University, Cleveland, OH. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Donna Kane, RN. Phone: 216-844-8609.

Case Western Reserve University, Cleveland, OH. CWRU-5Y97. Phase II trial using umbilical cord blood to evaluate the efficacy of transplantation to treat aplastic anemia and myelodysplastic syndromes patients. Eligible patients must have disease not responsive to medical therapy. Contact: Mary J. Laughlin. Phone: 216-844-8609.

Cedars-Sinai Medical Center, Los Angeles, CA. 02287. Phase II Trial of Paricalcitol in Myelodysplastic Syndromes to determine if an oral, relatively non-toxic, novel vitamin D3 compound, paricalcitol, (Zemplar) can improve red, white and platelet counts as well as decrease the risk of development of leukemia, without causing undue toxicity in patients with myelodysplastic syndromes (MDS). Patients will receive oral administration of paricalcitol in increasing doses. Contact: H. Phillip Koeffler, MD. Phone: 310-423-4609.

Children's Hospital of New York Presbyterian, New York, NY. 01-504. Phase II trial using fludarabine, busulfan, and anti-thymocyte globulin (ATG) to evaluate the efficacy of reduced intensity allogeneic stem cell transplantation to treat MDS. Eligible patients must have 1) MDS and ≤5% bone marrow myeloblasts at diagnosis; 2) minimum of ≥10% CD33 positivity; 3) adequate organ function (renal, hepatic, cardiac and pulmonary); 4) age ≤65 years; 5) matched family donor (5/6 or 6/6),unrelated donor (5/6 or 6/6), or cord blood donor (3/6, 4/6, 5/6, 6/6). Contact: Mitchel S. Cairo, MD. Phone: 212-305-8316.

Cleveland Clinic Foundation, Cleveland, OH. Phase II trial of combination therapy with arsenic trioxide (Trisenox) and gemtuzumab ozogamicin (Mylotarg) for the treatment of adult patients with advanced myelodysplastic syndromes. Contact: Liz Kuczkowski. Phone: 216-445-3795.

Comprehensive Cancer Institute. Huntsville, AL. Phase II study of arsenic trioxide (Trisenox) in patients with MDS. Contact: J.M. Waples, MD. Phone: 256-551-6546.

Dana-Farber Cancer Institute, Boston, MA. Phase I Study of Vaccination with Lethally Irradiated, Autologous Acute Myeloblastic Leukemia Cells Engineered by Adenoviral Mediated Gene Transfer to Secrete Human Granulocyte-Macrophage Colony Stimulating Factor in Patients with Advanced Myelodysplasia or acute Myelogenous Leukemia. This is a study to determine the feasibility of preparing lethally irradiated autologous myeloblastic leukemia cells engineered by adenoviral mediated gene transfer to secrete GM-CSF in patients with myelodysplasia or acute myelogenous leukemia. The study will also investigate the safety and biologic activity of vaccination with lethally irradiated, autologous myeloblastic leukemia cells engineered by adenoviral mediated gene transfer to secrete GM-CSF in patients with advanced myelodysplasia or acute myelogenous leukemia. Contact: Ilene Galinsky. Phone: 617-632-3902.

Duke University Medical Center, Durham, NC. Phase II trial to assess the value of non-myeloablative allogeneic therapy (mini bone marrow transplant) for patients with aplastic anemia or myelodysplastic syndromes. Patients must have severe disease to be eligible and may have either a matched sibling, mismatched family member, or large cord blood unit found for use on our trial. Contact: David A. Rizzieri, MD at Rizzi003@mc.duke.edu.

Fallon Clinic. Worcester, MA. PR01-09-010. Phase II study on the effectiveness of low dose Thalidomide combined with Erythropoietin in the treatment of anemia in patients with low and intermediate risk-1 myelodysplastic syndromes. Contact: Laszlo Leb, MD. Phone: 508-368-3168.

Fox Chase, BMT Program, Philadelphia, PA. 3297. Phase II trials using fludarabine-based regimen to evaluate the efficacy of mini-allogeneic blood stem cell transplantation to treat myelodysplastic syndromes. Eligible patients must have HLA identical donor available, be under age 70 and platelet or red cell transfusion dependent. Patients with matched related donors will be considered up to age 70 with Karnofsky Performance Scale >80%. Patients with matched unrelated donor will be considered to age 65 only. Contact: Marge Bellergeau, RN. Phone: 215-214-3122.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1297. Radiolabeled BC8 (anti-CD-45) Antibody Combined with Cyclophosphamide and Total Body Irradiation Followed by HLA-Matched Related or Unrelated Stem Cell Transplantation as Treatment for Advanced Acute Myeloid Leukemia and Myelodysplastic Syndrome. Phase II trial to determine the efficacy (as measured by survival and disease-free survival) and toxicity of a regimen of cyclophosphamide, TBI, plus the maximum tolerated dose of I labeled BC8 (anti-CD45) antibody in patients with AML

beyond first remission receiving HLA matched related hematopoietic stem cell transplants. Contact: J. Pagel, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1432. Phase I trial to determine the maximum tolerated dose of radiation delivered via BC8 antibody when combined with the non-myeloablative regimen of fludarabine, TBI+CSP/MMF in elderly patients (>50 and <70 years) with advanced AML or high risk MDS. Contact: J. Pagel, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1809. Phase I trial to determine the maximum tolerated dose of radiation delivered via BC8 antibody when combined with the non-myeloablative regimen of fludarabine, TBI+CSP/MMF in patients (<50 years) with advanced AML or high risk MDS. Contact: J. Pagel, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1591. Phase I trial to determine whether stable allogeneic engraftment from related and unrelated HLA-mismatched stem cell donors can be safely established using a non-myeloablative conditioning regimen plus escalating doses of the anti-CD52mAb Campath® in patients with hematologic malignancies. Contact: B. Sandmaier, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1732. Phase II trial to evaluate the efficacy of non-myeloablative allogeneic HCT from related and unrelated donors for the treatment of patients with MDS and MPD, who are not candidates for conventional allogeneic HCTG due to advanced age or serious comorbid conditions. Contact: B. Sandmaier, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1813. Phase III trial to compare the non-relapse mortality at 1-year after conditioning with TBI alone vs. fludarabine/TBI in heavily pretreated patients with hematologic malignancies at low/moderate risk for graft rejection who have HLA-matched related donors. Contact: B. Sandmaier, MD. Phone: 206- 288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1536. Transplantation of peripheral blood stem cells from related or unrelated volunteer donors in patients with "less advanced" MDS. Conditioning therapy includes busulfan (targeted to a pre-determined plasma level) and cytoxan (targeted BUCY); patients up to 65 years of age. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1596. Transplantation from related donors for high-risk patients with MDS. Conditioning includes a "non-myeloblative" regimen of fludarabine and 200 cGy of total body irradiation. Patients are evaluated individually for eligibility. Contact: David Maloney, MD, PhD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1478. Non-transplant therapy for "less advanced" MDS with ATG plus Enbrel. No age restrictions. Contact: H.J. Deeg, MD. Phone: 206-667-4324.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #117. Uses a combination of ATG and cyclophosphamide (CY) for the conditioning of patients with AA who are transplanted from HLA-identical family members. Contact: R. Storb, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #800. Uses a combination of ATG, CY and low dose (200 cGy) TBI for conditioning of patients with AA (up to 55 years of age) to be transplanted from unrelated donors. Contact: H.J. Deeg, MD. Phone 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1641. Transplantation from unrelated donors for high-risk patients with MDS. Conditioning will be with a "non-myeloablative" approach using 200 cGy of TB1 and fludarabine. No age restriction (other exclusion criteria exist). Contact: M. Maris, MD. Phone 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1723. Transplantation from related or unreleased donors for patients with advanced MDS or myeloproliferative disorders. Conditioning includes busulfan (targeted to a predetermined plasma level) and Cytoxan (targeted BUCY) with the addition of thymoglobulin; patients up to 65 years of age. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1781. Non-transplant therapy for "less advanced" transfusion-dependent MDS with DN-101 (Calcitriol). No age restrictions. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1628. Uses a targeted busulfan plus cyclophosphamide approach for conditioning. G-CSF-mobilized peripheral blood cells will be partially T-cell depleted with the intent of reducing the GVHD frequency and severity. Eligible are patients with MDS or high-risk AML who have an HLA-identical sibling donor. Contact: A. Woolfrey. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1913. Combines targeted busulfan with fludarabine plus Thymoglobulin. This protocol enrolls patients with MDS, myeloproliferative disorders, and other myeloid diseases. The objective is to further reduce non-relapse mortality. Patients with related and unrelated donors will be eligible. Contact: P. O'Donnell Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1668. Uses combinations of fludarabine and low-dose TBI for the conditioning of "older" patients or patients with clinically significant co-morbid conditions to be transplanted from related or unrelated donors. Contacts: M. Maris, B. Sandmaier. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1872. Uses a combination of ATG given for 4 days, followed by intermittent injection of Enbrel for patients with low or intermediate-1 risk disease by IPSS. Generally these are patients with <10% marrow blasts. The ATG is administered at the Center; the administration of Enbrel can be done by the patients themselves at home or in your office. Contact: B. Scott. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1888. Uses a combination of Enbrel plus arsenic trioxide (Trisenox) in patients with more advanced MDS (generally IPSS intermediate-2 or high risk) or patients who have failed to respond in Protocol #1872. Contact: B. Scott. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1926. Uses a combination of Enbrel plus 5-azacitidine (Vidaza) for patients with advanced MDS or patients who fail to respond to treatment in Protocol #1872. The Protocol is currently being reviewed by the IRB. Contact: B. Scott. Phone: 206-288-1024.

Froedtert Memorial Lutheran Hospital, Milwaukee, WI. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: David Vesole, MD. Phone: 414-805-4629.

Georgetown University, Washington, DC. Clinical and biologic effects of arsenic trioxide in MDS. Contact: B. Mavromatis, MD. Phone: 202-784-0124.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC#13935. Phase I/II Trial of Subcutaneous Decitabine (5-Aza-2'-deoxycytidine) Optimizing Genomic Methylation in Patients with Myelodysplastic Syndrome (MDS). Inclusion criteria: Histologically confirmed diagnosis of MDS or nonproliferative chronic myelomonocytic leukemia (CMML) according to FAB criteria, with IPSS category of Intermediate-2 or High. If cytogenetics are not available, patients with >10% and <30% marrow blasts are eligible. Soon to Open. Contact: Wendy Hodapp. Phone: 813-745-1706.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC#13937. A Pharmacokinetic and Pharmacodynamic Study of Oral CC-5013 (LENALIDOMIDE; REVLIMID) In Subjects with Low or Intermediate-1 Risk Myelodysplastic Syndromes. Inclusion criteria: Documented diagnosis of MDS that meets International Prognostic Scoring System (IPSS) criteria for Low to Intermediate-1 risk disease. Red blood cell (RBC) transfusion-dependent anemia defined as having received >4 transfusions of RBCs within 56 days of randomization of symptomatic anemia (Hgb <9.0 g/dl). Contact: Wendy Hodapp. Phone: 813-745-1706.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC#13727. A Phase IA/II, two-arm, multicenter, dose-escalation study of LBH589 administered intravenously on two dose schedules in adult patients with advanced hematologic malignancies. Inclusion criteria: Patients with a cytopathologically confirmed diagnosis of AML. MDS, (RAEB, RAEBT), ALL, CLL, CML, multiple myeloma, NHL including CTCL who are either relapsed after or refractory to standard therapy, and are considered inappropriate candidates for standard therapy. Patients with a cytopathologically confirmed diagnosis of AML. MDS, (RAEB, RAEBT) who are previously untreated but due to age, poor prognosis, or concurrent medical conditions are considered inappropriate candidates for standard induction therapy, or those who refuse standard induction therapy. Contact: Wendy Hodapp. Phone: 813-745-1706.

Indiana University Medical Center, Indianapolis, IN. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Larry Cripe, MD. Phone: 317-274-0901.

Johns Hopkins Oncology Center, Baltimore, MD. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Judith Karp. Phone: 410-502-5399.

Johns Hopkins Oncology Center, Baltimore, MD. J0136. Vaccination in peripheral stem cell transplant setting for acute myelogenous leukemia: The use of autologous tumor cells with an allogeneic GM-CSF producing bystander cell line. Contact: Julie Yerian. Phone: 410-614-1766.

Johns Hopkins Oncology Center, Baltimore, MD. J0255. Phase II study of the farnesyl transferase inhibitor Zarnestra in previously untreated poor-risk acute myeloid leukemia and myelodysplastic syndromes. Contact: Jackie Greer. Phone: 410-614-1329.

Johns Hopkins Oncology Center, Baltimore, MD. J0051. Dose finding study of bryostatin-1 and GM-CSF in refractory myeloid malignancies. Contact: Dr. B. Douglas Smith. Phone: 410-614-5068.

Johns Hopkins Oncology Center, Baltimore, MD. J9950. Phase I dose de-escalation to minimal effective pharmacologic dose trial of sodium phenylbutyrate in combination with 5-azacytidine in patients with myelodysplastic syndromes. Contact: Tianna Dauses. Phone: 410-502-7110.

Johns Hopkins Oncology Center, Baltimore, MD. J9879. Phase I, dose-finding trial of sodium phenylbutyrate (NSC 657802) in combination with all trans-retinoic acid (ATRA, NSC 122758) in patients with myelodysplastic syndromes (MDS) and acute myeloid leukemia. Contact: Dr. Steven Gore. Phone: 410-955-8781.

Johns Hopkins Oncology Center, Baltimore, MD. J0253. Phase I clinical-laboratory study of the histone deacetylase (HDA) inhibitor MS-275 in adults with refractory and relapsed hematologic malignancies. Contact: Dr. Judith Karp. Phone: 410-502-7726.

Johns Hopkins Oncology Center, Baltimore, MD. J0252. Phase II study of the farnesyl transferase inhibitor Zarnestra in complete remission following induction and/or consolidation chemotherapy in adults with poor-risk acute myelogenous leukemia (AML) and high-risk myelodysplasias. Contact: Jackie Greer. Phone: 410-614-1329.

Johns Hopkins Oncology Center, Baltimore, MD. J9852. Granulocyte-macrophage colony stimulating factor (rhu-GM-CSF) after T-lymphocyte depleted allogeneic BMT for Myelodysplastic syndromes (MDS). Contact: B. Douglas Smith. Phone: 410-614-5068.

Johns Hopkins Oncology Center, Baltimore, MD. J0443. A dose-Finding Trial of the Histone Deacetylase Inhibitor MS-275 in Combination with 5-Azacytidine (5AC, NSC 102816) in Patients with Myelodysplastic syndromes (MDS) and Acute Myeloid Leukemia (AML). Contact: Dr. Steven Gore. Phone: 410-955-8781.

Los Angeles Hematology and Oncology Assoc., Los Angeles, CA. Phase I/II study of arsenic trioxide in combination with cytosine arabinoside in patients with MDS. Contact: C. Gota, MD. Phone: 818-409-0105.

MD Anderson Cancer Center, Houston, TX. Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Stefan Faderl, MD. Phone: 713-563-4613.

MD Anderson Cancer Center, Houston, TX. Open-Label, Phase II Study to Evaluate The Efficiency and Safety of the Farnesyltransferase Inhibitor Zarnestra (R115777) in Subjects with High-Risk Myelodysplastic Syndrome (MDS). Contact: Razelle Kurzrock, MD.

MD Anderson Cancer Center, Houston, TX. ID02-266. Therapy of inversion (16) and T (8:21) AML/MDS with fludarabine and Ara-C. Contact Elihu H. Estey, MD. Phone: 713-792-7544.

MD Anderson Cancer Center, Houston, TX. Phase I/II Study of PR1 (NSC698102) Human Leukemia Peptide Vaccine with Incomplete Freund's Adjuvant (NSC 675756). Contact: Jeffrey Molldrem, MD. Phone: 713-745-4820.

MD Anderson Cancer Center, Houston, TX. Phase II Open-Label Study of the Intravenous Administration of Homoharringtonine (CGX-635) in the Treatment of Myelodysplastic Syndrome (MDS). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Phase II Study of Arsenic Trioxide in the Treatment of Myelodysplastic Syndromes. Contact: Miloslav Beran, MD. Phone: 713-792-2248.

MD Anderson Cancer Center, Houston, TX. Phase II, Multicenter, Open-Label Study of the Safety and Efficacy of High-Dose Pulse Administration DN-101 (Calcitriol) in Patients with Myelodysplastic Syndrome. Contact: Guillermo Garcia-Manero, MD. Phone: 713-745-3428.

MD Anderson Cancer Center, Houston, TX. Randomized, Open-Label, Phase III Trial Of Decitabine (5-AZA-2'Deoxycytidine) Versus Supportive Care In Adults With Advanced-Stage Myelodysplastic Syndrome. Contact: Jean-Pierre Issa, MD. Phone: 713-745-2260.

MD Anderson Cancer Center, Houston, TX. Safety and Efficacy Trial of Bevacizumab: Anti-VEGF Humanized Monoclonal Antibody (NSD 704865) Therapy for Myelodysplastic Syndrome (MDS). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Phase II Study of Neumega (Oprelvekin)(Interleukin-11) in Patients with Myelodysplastic Syndrome. Contact: Razelle Kurzrock, MD. Phone: 713-794-1226.

MD Anderson Cancer Center, Houston, TX. Multicenter Phase I/II Study Of Continuous Oral Administration Of SCH 66336 In Patients With Advanced Myelodysplastic Syndrome, Acute Myelogenous Leukemia, Chronic Myelogenous Leukemia In Blast Crisis, Acute Lymphoblastic Leukemia. Contact: Jorge Cortes MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Phase II Study of Intravenous Homoharringtonine in Chronic Myelogenous Leukemia (CML). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Therapy of Hypereosinophilic Syndrome, Polycythemia Vera, Atypical CML or CMML with PDGF-R Fusion Genes, or Mastocytosis with Gleevec (STI571). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. DCTER Chemotherapy In Patients Ages 1 Through 49 With Untreated AML or High-Risk Myelodysplasia. Contact: Elihu Estey, MD. Phone: 713-792-7544.

MD Anderson Cancer Center, Houston, TX. Phase II study of clofarabine in combination with cytarabine (Ara-C) in pts ≥50 yrs with newly diagnosed and previously untreated acute myeloid leukemia (AML) and high-risk myelodysplastic syndrome (MDS) (≥10% bone marrow blasts). Contact: Stefan Faderl, MD. Phone: 713-745-4613.

MD Anderson Cancer Center, Houston, TX. DM02-203. Phase Ia, Open-Label, 3-Arm, Dose Escalation Study of PTK787/ZK 222584. Contact: Francis Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center, Houston, TX. ID03-0044. Phase I Clinical Trial of Oral Suberoylanilide Hydroxamic Acid (SAHA) in Patients with Advanced Leukemias. Contact: Guillermo Garcia-Manero, MD. Phone: 713-745-3428.

MD Anderson Cancer Center, Houston, TX. DM01-646. Phase I Study of ABT-751 in Patients With Refractory Hematologic Malignancies. Contact: Francis Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center, Houston, TX. ID99-059. Phase II trial using ATG and Fludarabine or Cyclosporine to evaluate the efficacy of immunosuppression to treat aplastic anemia and myelodysplastic syndromes patients. Eligible patients must have RA or RARS and low blood counts. Contact: Jeffrey Molldrem, MD. Phone: 713-745-4820.

MD Anderson Cancer Center, Houston, TX. ID99-059. Phase II trial using ATG/CSA; ATG/Fludarabine. Eligible patients must have MDS of subtype RA, blasts ≤5% in bone marrow that require ≥unit of PRBC/month for ≥2 months, platelet count ≤50,000/m^3, or neutrophil count ≤500/m^3, IPSS score ≥2. Contact: Jeffery Molldrem, MD. Phone: 713-745-4820.

Memorial Sloan-Kettering Cancer Center, New York, NY. 99-057. Phase I study of salicylate for adult patients with advanced myelodysplastic disorders, acute myelogenous leukemia or chronic lymphocytic leukemia. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

Memorial Sloan-Kettering Cancer Center, New York, NY. 00-116. Pilot study of FR901228 or Depsipeptide (NSC#630176) for adult patients with advanced hematologic disorders. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

Memorial Sloan-Kettering Cancer Center, New York, NY. 02-063. Tolerability and PK/PD of multiple oral doses of CT53518 in patients with acute myelogenous leukemia. Contact: Mark Heaney, MD, PhD. Phone: 212-639-2275.

Mount Sinai Medical Center, New York, NY. Phase I-II Pilot Study of Divalproex Sodium and All-Trans-Retinoic Acid (ATRA) in Relapsed or Refractory Acute Myeloid Leukemia (except M3, FAB Classification). Contact: Lewis Silverman, MD. Phone: 212-241-5520.

Mount Sinai Medical Center, New York, NY. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Lewis Silverman, MD. Phone: 212-241-5520.

National Heart, Lung, and Blood Institute, Bethesda, MD. 04-H-0026. Randomized Trial of Daclizumab versus ATG for Myelodysplastic Syndrome. Clinical trial comparing the effectiveness of treatment with either a new immunosuppressive drug (Daclizumab) or antithymocyte globulin (ATG) for patients with myelodysplastic syndrome. The study may help increase blood counts, reduce anemia symptoms, and/or reduce dependence on immunosuppressive medications and transfusions. If you are determined to be eligible to participate and you agree to join, it will be determined by chance whether you receive either daclizumab or ATG. If the treatment you are assigned does not work, you may subsequently receive the other treatment. Contact: Laura Wisch. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 01-H-0162. Stem Cell Transplantation for Older Patients with Myelodysplastic Syndrome. If you are 55 to 75 years of age and have been diagnosed with MDS, you may be eligible for a transplant procedure designed to decrease a major transplant complication, graft-versus-host disease (GVHD). Under evaluation is a novel method of treating your donor's cells prior to transplant. You must have an HLA-matched brother or sister to participate. We will do the blood testing free of charge to see if your sibling is a match upon request. Contact: Laura Wisch. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 04-H-0112. Stem Cell Transplantation and T-Cell Add Back to Treat Myelodysplastic Syndromes. Clinical trial designed to decrease graft versus host disease, promote engraftment, and improve immune system recovery following a bone marrow stem cell transplant. You must have an HLA matched brother or sister donor to participate in this trial. Contact: Laura Wisch. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 03-H-0209. Stem Cell Transplant for MDS from a partially HLA-matched family member. Many patients are not considered for a stem cell transplant because an HLA-matched sibling or unrelated donor is unavailable. For such patients, the only curative option is a transplant from a partially HLA-matched family member. If you are 10–50

MDS

Membership Information

The MDS Foundation would like to have you as a member. Membership is US$35 a year for physicians and other professionals. Patients, their families, and others interested in MDS may join at the reduced rate of $20.

Membership benefits include quarterly issues of the *MDS News*, a special subscription rate of $109 for *Leukemia Research* (a substantial discount from the current subscription rate of $1,193), and the worldwide Centers of Excellence patient referral service.

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

The MDS Foundation
36 Front Street, P.O. Box 353
Crosswicks, NJ 08515

Phone: 1-800-MDS-0839
Fax: 609-298-0590
Outside the US only:
609-298-1035

years of age and have been diagnosed with advanced myelodysplastic syndrome, you may be eligible for a clinical trial of a transplant procedure that evaluates using peripheral blood stem cells from an HLA-mismatched family donor. Eligible patients are not asked to pay for their medical treatment and hospital costs. Contact: Laura Wisch. Phone: 301-402-0797.

New York Medical College/Westchester Medical Center, Valhalla, NY. Phase II study of Gemtuzumab Ozogamicin and Cytarabine in patients with high risk CD33+ acute myelogenous leukemia and high risk myelodysplastic syndromes. Contact: Dr. Karen Seiter. Phone: 914-493-7514.

New York Medical College/Westchester Medical Center, Valhalla, NY. Phase I/II study of a non-myeloablative regimen of pentostatin, mitoxantrone and cytarabine for engraftment of allogeneic hematopoietic progenitor cells in patients with acute leukemia, chronic myelogenous leukemia and myelodysplasia: The mini allo protocol. Contact: Dr. Delong Liu. Phone: 914-493-7514.

New York Presbyterian Hospital, New York, NY. Phase I/II trial of Trisenox in combination with low dose Ara-C for the treatment of high-risk MDS and poor prognosis AML in patients >60 years. Contact: Gail Roboz, MD. Phone: 212-746-3126.

Oregon Health & Science University, Portland, OR. 8346. Phase 1-2a Study of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes (MDS). Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 7944. A Randomized, Double-blind Trial of Fluconazole vs. Voriconazole for the Prevention of Invasive Fungal Infections in Allogeneic Blood and Marrow Transplant Patients. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 8186. A Phase III Randomized, Multicenter Trial Comparing G-CSF Mobilized Peripheral Blood Stem Cell with Marrow Transplantation from HLA Compatible Unrelated Donors. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 8343. Prolonged Mycophenolate Mofetil and Truncated Cyclosporine Postgrafting Immunosuppression to Reduce Life-Threatening GvHD after Unrelated Donor Peripheral Blood Cell Transplantation using Nonmyeloablative Conditioning for Patients with Hematologic Malignancies and Renal Cell Carcinoma–A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 7881. Donor Lymphocyte Infusion for the Treatment of Malignancy After Hematopoietic Cell Transplantation Using Non-Myeloablative Conditioning–A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 7039. Randomized Controlled Trial of Posaconazole (SCH56592) vs. Standard Azole Therapy for the Prevention of Invasive Fungal Infections Among High-Risk Neutropenic Patients. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 4352. Transplantation of Unrelated Donor Marrow or Placental Blood Hematopoietic Stem Cells for the Treatment of Hematological Malignancies. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 8119. Phase III trial to compare the non-relapse mortality at 1-year after conditioning with TBI alone vs. fludarabine/TBI in heavily pretreated patients with hematologic malignancies at low/moderate risk for graft rejection who have HLA-matched related donors. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Roswell Park Cancer Institute, Buffalo, NY. PTK787. Phase II study of an oral VEGF agent in myelodysplastic syndromes. Contact: Maria Baer, MD. Phone: 716-845-8840.

Roswell Park Cancer Institute, Buffalo, NY. RPC-02-03. Treatment of anemia in patients with low-and intermediate-risk MDS with darbepoetin alfa. Multicenter, phase II trial also open at the University of Alabama (Birmingham), Loyola University Medical Center (Chicago), and Rochester General Hospital (Rochester, NY). Contact: Maria Baer, MD. Phone: 716-845-8840.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 99-14. Pilot study of Thalidomide (Thalomid) combined with Pentoxyfilline, Ciprofloxacin and Dexamethasone (PCD) in patients with myelodysplastic syndromes. This is a phase II trial using anticytokine and antiangiogenic therapy to evaluate the efficacy of Thalidomide (Thalomid) to treat MDS. Eligible patients must have MDS (RA, RARS or RAEB). Addendum: Reduced dose of Pentoxyfilline (400 mg po TID), No Cipro, No Decadron. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 801-001. Multicenter, open-label, dose-escalation study to determine the safety and preliminary efficacy of CC-1088 in treatment of myelodysplastic syndromes. Eligible patients must have RA or RARS. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2000-04. Phase IIB study using Thymoglobulin in transfusion dependent patients with myelodysplastic syndrome. Open to FAB types RA, RARS, RAEB. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2000-11. Pilot study to test the efficacy of infliximab (Remicade) in patients with low-risk myelodysplastic syndromes. Eligible patients must be transfusion dependent or hemoglobin ≤9 grams, and an IPSS score ≤1.5, and cannot have a history of clinically significant cardiac disease or CHF. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2001-12. Pilot study to determine the clinical effects of the proteasome inhibitor PS-341 in patients with myelodysplastic syndromes. All FAB types are eligible. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2001-13. Randomized, open-label, phase III trial of Decitabine (5-Aza-2'-Deoxycytidine) versus supportive care in adults with advanced-stage myelodysplastic syndromes. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2002-02. Phase II trial to evaluate the efficacy of Trisenox in patients with MDS, followed by thalidomide in non-responders. Eligible patients must belong to IPSS int 1 or higher, have adequate hepatic and renal function as defined by specific laboratory parameters, and have an ECOG PS of 0–2. Patients will receive Trisenox alone for six months. Patients who do not respond will have thalidomide added to the regimen at 6 months. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2000-08. Pilot Study to Test the Efficacy of Gleevec (STI 571) in Patients with Myelodysplastic Syndromes. Given the clinical and molecular similarities between CML and CMMoL, especially those related to the activation of tyrosine kinase induced downstream events suggest that suppression of the same kinase in CMMoL by using an agent like Glivec may produce clinical benefit in these individuals. We propose to test this hypothesis by treating one cohort of 15 CMMoL patients with Gleevec or STI571 at 400 mg po daily. The second cohort of 15 patients [having translocation (5;12)] will likewise receive Gleevec or STI571 at 400 mg po daily. Response assessment will be made every 8 weeks and in case of disease progression, the patient will be removed from the study. Responding patients or those with stable disease will be treated for one year at least with the drug provided by Novartis. After the one-year period, further therapy will depend upon the discretion of the physician. Disease progression is defined as occurrence of acute leukemia, increase in BM blasts by 50% over pre-therapy values if the blast count was >5% to begin with, and worsening cytopenia. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2002-04. Pilot Study to Test the Efficacy of a Combination of Gleevec with Thalidomide in Patients with Idiopathic Primary Myelofibrosis, Myelofibrosis with Myeloid Metaplasia and Myelodysplastic Syndromes Who Present With Myelofibrosis. We propose to use a combination of thalidomide and Gleevec for the treatment of patients with MMM and MDS who present with Grade 3+ and greater myelofibrosis. The rationale for this combination is that the anti-angiogenic and anti-TNF effects of thalidomide may be potentiated by the anti-TGF-β, anti-PDGF effects of Gleevec to reduce marrow fibrosis in this group of patients. We propose to treat 30 patients on this study using Thalidomide starting at a dose of 100 mg per day and increasing to 400 mg per day and Gleevec at 600 mg per day. Treatment will be continued for one year or until disease progression. Bone marrows will be obtained at 16 weeks and then at the end of the study. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS2003-01. Pilot Study to Determine the Clinical Efficacy of Coenzyme Q10 in Patients with Myelodysplastic Syndromes. We propose to treat 40 patients belonging to RA and or RARS or low risk and Int-1 categories of MDS patients with CoQ10 at a starting dose of 300 mg escalating as tolerated to 1200 mg po qday. Patients will begin taking 300 mg po BID with meals for Days 1–3. On Days 4–6, patients will take 300 mg po TID with meals. On Day 7 and onward, patients will take 300 mg po QID with meals. Patients will be treated for up to a year unless intolerable side effects and/or disease progression are noted. Responses will be continuously evaluated by weekly CBCs and bone marrows repeated every 16 weeks. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Stanford University Medical Center, Stanford, CA. Phase I/II trial: Decitabine treatment of MDS. Eligibility: IPSS High, Intermediate-2. Contact: Kathy Dugan, RN. Phone: 650-723-8594.

Stanford University, Stanford, CA. Study of DARBEPOETIN ALFA in Patients with MDS. Primary objectives are 1) to assess erythroid response to DARBEPOETIN ALFA, as determined by changes in hemoglobin and/or red blood cell (RBC) transfusion-dependence. 2) to describe the safety profile of DARBEPOETIN ALFA in patients with MDS. Phase II trial. Eligibility: IPSS Low, Intermediate-1. Contact: Sylvia Quesada, RN. Phone: 650-725-4041.

Stanford University, Stanford, CA. Phase II trial: Exjade (ICL670) oral iron chelator treatment of MDS patients with iron overload. Contact: Kathy Dugan, RN. Phone: 650-723-8594.

St. Francis Hospital, Hartford, CT. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Bilgrami. Phone: 860-714-4680.

St. Jude Children's Research Hospital, Memphis, TN. DSAML. Treatment of children with down syndrome (DS) and acute myeloid leukemia (AML), myelodysplastic syndrome (MDS), and transient myeloproliferative disorder (TMD). Contact: Nobuko Hijiya, MD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. AML02. Collaborative trial for the treatment of patients with newly diagnosed acute myeloid leukemia or myelodysplasia. Contact: Jeffrey Rubnitz, MD, PhD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. HAPSCT. Phase III randomized trial to evaluate haplo-identical stem cell transplantation utilizing purified CD34+ hematopoietic cells for patients with hematologic malignancies: a randomized study comparing positive and negative selection methodologies. Contact: Gregory Hale, MD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. MUDSCT. Phase III controlled trial to evaluate hematopoietic stem cell transplantation for patients with hematologic malignancies: a comparison of T-cell depleted bone marrow with unmanipulated bone marrow. Contact: Edwin Horwitz, MD, PhD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. REFSCT. Pilot study to evaluate haploidentical stem cell transplantation utilizing T-Cell depletion as therapy for patients with refractory hematological malignancies. Contact: Ely Benaim, MD. Phone: 901-495-3300.

Texas Oncology Medical City Dallas Hospital, Dallas, TX. D-0007. Randomized, open-label, Phase III trial of decitabine (5-aza-2'-deooxycytidine) versus supportive care in adults with advanced-stage myelodysplastic syndrome. This Phase III trial evaluates the efficacy of decitabine to treat MDS. Eligible patients may have de novo or secondary MDS. Growth factors (G-CSF, erythropoietin), steroids, hormones or chemotherapy for treatment of MDS are not allowed for 2 weeks prior to enrollment. Contact: Ronda Waldrop. Phone: 972-566-7790.

Texas Oncology Medical City Dallas Hospital, Dallas, TX. SMC-101-1020. Open-label, prospective, stratified, randomized, controlled, multicenter, phase IIB study of the impact of Thymoglobulin therapy on transfusion needs of patients with early myelodysplastic syndrome. This protocol evaluates Thymoglobulin therapy for 4 days. Eligibility includes low risk MDS (RA, RAEB <10%), IPSS <1.0, transfusion dependence. No prior chemotherapy allowed. Contact: Ronda Waldrop. Phone: 972-566-7790.

Texas Oncology Medical City Dallas Hospital, Dallas, TX. T-MDS-001. Multicenter, randomized, double-blind, placebo-controlled trial comparing best supportive care and thalidomide for the treatment of anemia in patients with myelodysplastic syndrome followed by an open-label treatment with thalidomide. Recently, treatment with thalidomide has been reported to improve the anemia in some patients with MDS. The purpose of this study is to further evaluate the effect of thalidomide or placebo pills (50:50 chance) for 24 weeks. Thereafter, all subjects can receive thalidomide for an additional 24 weeks. The effect of treatment on transfusions and quality of life will be evaluated. Contact: Ronda Waldrop. Phone: 972-566-7790.

Tufts-New England Medical Center, Boston, MA. Reduced intensity bone marrow transplantation as curative therapy for Myelodysplastic Syndromes. Patients under the age of 75 in good physical health with an eligible donor may participate. Contact: Geoffrey Chan, MD. Phone: 617-636-2520.

University of Alabama at Birmingham Comprehensive Cancer Center, Birmingham, AL. Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Peter Emanuel, MD. Phone: 205-975-2944.

University of Arizona Cancer Center, Tucson, AZ. HSC #02-11. Safety and efficacy trial of bevacizumab: anti-vegf humanized monoclonal antibody therapy for MDS. Contact: Daruka Mahedevan, MD. Phone: 520-626-2340.

University of California at Los Angeles (UCLA) Medical Center, Los Angeles, CA. Randomized, multicenter, double-blind, placebo controlled trial assessing the safety and efficacy of thalidomide (Thalidomid) for the treatment of anemia in patients with myelodysplastic syndromes. Recently, treatment with thalidomide has been reported to improve the anemia in some patients with MDS. The purpose of this study is to further evaluate the effect of thalidomide or placebo pills (50:50 chance) for 24 weeks. Thereafter, all subjects can receive thalidomide for an additional 24 weeks. The effect of treatment on transfusions and quality of life will be evaluated. The most common side effects of thalidomide include severe birth defects, drowsiness, weakness, rash, shortness of breath, fluid retention, constipation, low blood pressure, decreased white blood counts, slow heart beats and nerve damage. Contact: Ron Paquette, MD. Phone: 310- 825-5608.

University of Chicago, Chicago, IL. 2978. A pivotal randomized study of Lonafarnib (SCH 66336) vs. placebo in the treatment of subjects with Myelodysplastic Syndromes (MDS) or Chronic Myelomonocytic Leukemia (CMML) who are platelet transfusion dependent with or without anemia. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Chicago, Chicago, IL. 13172B. Phase 1–2a of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Chicago, Chicago, IL. 12981A. A Phase II study of an oral VegF receptor tyrosine kinase inhibitor (PTK787/2K222584) (IND #66370, NSC #719335) in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Louisville, Louisville, KY. #541.02. Pilot study of arsenic trioxide and amifostine for the treatment of myelodysplastic syndromes. Eligible patients must have a confirmed diagnosis of MDS. *For patients with lower-risk only:* documented red blood cell dependence, defined as the inability to maintain a hematocrit of >25% without transfusion support and patients with serum erythropoietin less than 200 IU/mL at screening should have failed to respond to a trial of recombinant erythropoietin (EPO) administered in accordance with institutional guidelines. Patients must have an ECOG PS 0-2 and adequate hepatic and renal function as evidenced by specific laboratory criteria. Contact: R. Herzig, MD. Phone: 800-234-2689.

University of Michigan Comprehensive Cancer Center, Ann Arbor, MI. Phase II trial of combination therapy with arsenic trioxide (Trisenox) and gemtuzumab ozogamicin (Mylotarg) for the treatment of adult patients with advanced myelodysplastic syndrome. Contact: Harry P. Erba, MD, PhD.

University of Pennsylvania Cancer Center, Philadelphia, PA. A pilot study of valproic acid in patients with MDS. Contact: Selina Luger, MD. Phone: 215-662-6348.

University of Pennsylvania Cancer Center, Philadelphia, PA. Pilot study of arsenic trioxide in patients with MDS. Contact: Selina Luger, MD. Phone: 215-662-6348.

University of Texas Health Science Center at San Antonio, San Antonio, TX. Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Natalie Callander, MD. Phone: 210-617-5300 Ext. 4720.

University of Texas, UT Health Science Center, San Antonio, TX. Randomized, double-blind, phase II study of the matrix metalloproteases inhibitor Prinomastat in patients having myelodysplastic syndromes. Eligible patients must be over 18 years of age and have a diagnosis of MDS of at least 8 weeks duration, hemoglobin <9.0 g/dL (or be transfusion dependent) with adequate renal/hepatic function of serum creatinine less than or equal to 1.5 mg/dL and serum total bilirubin less than or equal to 2.0 mg/dL. Contact: Natalie Callander, MD. Phone: 210-567-4848.

University of Washington, Seattle, WA. UW-26-245-B. Phase I trial using subcutaneous, outpatient injection to evaluate the efficacy of Interleukin-2 to treat MDS. Eligible patients must have either refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, or chronic myelomonocytic leukemia; more than 30 days since any prior treatment for MDS; Karnofsky performance status >70; serum creatinine <2.0 mg/dL; bilirubin ≤1.6 mg/dL or SGOT ≤150. Contact: John A. Thompson, MD. Phone: 206-288-2015.

University of Wisconsin, Department of Medicine, Madison, WI. HO 02403. Phase II trial using Doxercalciferol (Vitamin D) for treating MDS. Participants must have no prior exposure to doxercalciferol and must be at least 18 years old. Contact: Mark Jucket, MD. Phone: 608-263-1836.

Vanderbilt University Medical Center, Nashville, TN. Phase II study of arsenic trioxide in myelodysplasia. Contact: Shubhada M. Jagasia, MD. Phone: 615-322-4752.

Wake Forest University School of Medicine, Winston-Salem, NC. CCCWFU-29203. Orthomolecular Vitamin D in Low-Risk Myelodysplastic Syndrome: Phase II trial using cholecalciferol (Vitamin D3) to evaluate the efficacy of 2000 IU Vitamin D3 daily for 6 months to treat MDS. Eligible patients must have MDS; IPSS score 0–1.0; life expectancy >1 year; no other concurrent therapy for MDS; no history of hypercalcemia. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

Washington University School of Medicine, St. Louis, MO. Multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Alisa Ruddell. Phone: 314-454-4095.

Washington University School of Medicine, St. Louis, MO. This study seeks individuals with bone marrow failure. Participants are asked to submit a sample of blood for gene and telomere analysis. Researchers are investigating the hTR gene found on chromosome 3. Participants are also asked to submit their medical and family history information. This information is used to make correlations among the participants' clinical features and the gene and telomere analysis. Contact: Jennifer Ivanovich, MS. Phone: 314-454-5076.

Western Pennsylvania Cancer Institute, Pittsburgh, PA. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Michelle Marietti, RN. Phone: 412-578-5346.

European Trials

AUSTRALIA

The Newcastle Mater Miseriecordiae Hospital, New South Wales. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Arno Enno. Phone: +61 2 4921 1215.

Princess Alexandra Hospital, Queensland. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Anthony Mills. Phone: +61 7 3240 2086.

Royal Adelaide Hospital, South Australia. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Noemi Horvath. Phone: +61 8 8222 3550.

The Alfred Hospital, Victoria. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Andrew Spencer. Phone: +61 3 9276 3392.

The Royal Perth Hospital, Western Australia. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Richard Herrman, MD. Phone: +61 8 9224 2405.

BELGIUM

Cliniques Universitaires Saint-Luc, Bruessel. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Ferrant. Phone: 32 2 764 1810 (1880).

ENGLAND

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Cloretazine in high grade MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Zarnestra in high grade MDS & AML. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Revlimid in 5Q-Syndrome. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Reduced intensity conditioned transplantation in MDS using Fludara, IV Campath and Busulphan as conditioning. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Multi-center study of the role of 5-Azacitidine in high risk MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Randomized study of GCSF + Epo versus supportive care in low risk MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Professor Ghulam J. Mufti. Phone: 44(0)207-346-3080.

The Royal Bournemouth Hospital. Multi-centre study of the role of 5-Azacytidine in high risk MDS. Contact: Sally Killick, MD. Phone: 44 (0) 11202 704783.

The Royal Bournemouth Hospital. Multi-centre trial of CEP-701 in older patients with AML. Contact: Sally Killick, MD. Phone: 44 (0) 11202 704783.

FRANCE

Groupe Français des Myelodysplasies. A phase II multi-center study of treatment of anemia in low risk MDS by the combination of Epo and all-trans retinoic acid. Contact: Lionel Ades, MD. Phone: +33 1 48 95 70 55/51. lionel.ades@avc.aphp.fr

Groupe Français des Myelodysplasies. A phase II multi-center study of low dose Thalidomide for the treatment of low risk MDS. Contact: Didier Bouscary, MD. Phone: +33 1 58 41 11 96. bouscary@cochin.inserm.fr

Groupe Français des Myelodysplasies. A phase II multi-center study of treatment of anemia in low risk MDS by Darbepoetin Alpha. Contact: Lionel Mannone, MD. Phone: +33 4 92 03 58 46. mannone.l@chu-nice.fr

Groupe Français des Myelodysplasies. A phase III randomized trial comparing 5 azacytidine and conventional treatment (best supportive care alone, or with low dose AraC, or with intensive chemotherapy). Contact: Pierre Fenaux, MD. pierre.fenaux@avc.ap-hp.fr

Groupe Français des Myelodysplasies. A phase II study of intensive chemotherapy combined to quinine in high risk MDS with PGP expression. Contact: P. Fenaux or S. de Botton. s.de-botton@voila.fr

Institute Paoli Calmettes, Marseilles. Phase I/II multi-center study of arsenic trioxide in patients with MDS. Contact: Norbert Vey, MD. Phone: +33 4 91223695.

Institute Paoli Calmettes, Marseilles. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Norbert Vey, MD. Phone: +33 4 91223695.

Institute Paoli Calmettes, Marseilles. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Norbert Vey, MD. Phone: +33 4 91223695.

Chu Purpan, Toulouse. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Guy Laurent, MD. Phone: +33 5 61772078.

Chu De Nantes, Nantes. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Beatrice Mahe, MD. Phone: +33 2 40083252.

Chu De Lille, Lille. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Bruno Quesnel, MD. Phone: +33 3 20446640.

Hôpital Cochin, Paris. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Francois Dreyfus, MD. Phone: +33 1 58412120.

GERMANY

Heinrich-Heine University Düsseldorf. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Norbert Gattermann, MD. Phone: +49 211 811 6500.

Heinrich-Heine University Düsseldorf. Phase II Trial of Valproic Acid as a Monotherapy or in Combination with All-trans Retinoic Acid for the treatment of Myelodysplastic Syndromes. Contact: Norbert Gattermann, MD. Phone: +49 211 811 6500.

University Hospital Freiburg. Phase II study of low-dose intravenous decitabine in patients aged >60 years with acute myeloid leukemia who are not eligible for standard induction chemotherapy. Contact: Michael Lübbert, MD, PhD. Phone: +49-761-270-3279.

University Hospital Freiburg. Intravenous low-dose decitabine versus supportive care in elderly patients with primary Myelodysplastic Syndrome (MDS) (>10% blasts or high-risk cytogenetics), secondary MDS or Chronic Myelomonocytic Leukemia (CMML) who are not eligible for intensive therapy: an EORTC-German MDS Study Group randomized Phase III study. Contact: Michael Lübbert, MD, PhD. Phone: +49-761-270-3279.

University Hospital Hamburg. Allogeneic stem cell transplantation after toxicity-reduced conditioning regimen with treosulfan and fludarabine for patients with MDS or sAML, who were not eligible for a standard conditioning regimen: a phase II study. Contact: Nicolaus Kröger, MD. Phone: +49-40-42803-4851.

University Hospital Hamburg. Dose-reduced versus standard conditioning followed by allogeneic stem cell transplantation in patients with MDS or sAML. A randomized phase III study (started May 2004). Contact: Nicolaus Kröger, MD. Phone: +49-40-42803-4851.

University Hospital Benjamin Franklin, Berlin. SAKK 33/99. Antithymocyte Globulin (ATG) and Cyclosporine (CSA) to treat patients with Myelodysplastic Syndrome (MDS). A randomized trial comparing ATG & CSA with best supportive care. Contact: Prof. Dr. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

University Hospital Benjamin Franklin, Berlin. Phase II clinical trial using vaccination with Wilms-Tumor-Gen 1 (WT1) derived peptide in patients with acute myeloid Leukemia and Myelodysplastic Syndrome. Contact: Prof. D. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

University Hospital Benjamin Franklin, Berlin. AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous Azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Prof. Dr. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

Universitätsklinikum Carl Gustav Carus, Dresden. AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trials for subcutaneous Azacitidine plus best supportive care versus conventional care regimens plus best supportive care for treatment of MDS. Contact: Uwe Platzbecker, MD. Phone: +49-351-458-2321.

Universitätsklinikum Carl Gustav Carus, Dresden. 06011 (EORTC). Intravenous low-dose decitabine versus supportive care in elderly patients with primary Myelodysplastic Syndrome (MDS) (>10% blasts or high-risk cytogenetics), secondary MDS or Chronic Myelomonocytic Leukemia (CMML) who are not eligible for intensive therapy: an EORTC-German MDS study group randomized Phase III study. Contact: Uwe Platzbecker, MD. Phone: +49-351-458-2321.

Universitätsklinikum Carl Gustav Carus, Dresden. 2003/4. Radioimmunotherapy with Re-188-anti-CD66-antibody for conditioning of AML and MDS patients above the age of 55 prior to stem cell transplantation. Contact: Martin Bornhäuser, MD. Phone: +49-351-458-2321.

Universitätsklinikum Carl Gustav Carus, Dresden. 2003/2. Tacrolimus and Mycophenolate mofetil as Graft-versus-Host disease Prophylaxis for patients with Myelodysplastic Syndrome (MDS) or Acute Myeloid Leukemia (AML) receiving conditioning with Fludarabine and targeted intravenous Busulfan and Hematopoietic stem cells from HLA-compatible siblings or unrelated donors. Contact: Martin Bornhäuser, MD. Phone: +49-351-458-2321.

HUNGARY

Semmelweis University School of Medicine, Budapest. Investigation of the multifactorial cause of iron overload by testing HFE gene mutations: C282Y and H63D, determination of copper and coeruloplasmin level, analysis of transferring receptor mutation and also TNFalpha promoter gene polymorphism in MDS patients. Contact: Judit Varkonyi, MD, PhD. Phone/Fax: 361-355-8251.

ITALY

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. A Phase III clinical trial comparing a single, weekly dose of recombinant erythropoietin alpha (40.000 units) alone versus the combination of this treatment plus low-dose thalidomide for anemic, low-risk MDS. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 882-410295-539.

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. AZA PH GL 2003 CL 001. A multicenter, randomized, open label, parallel-group, Phase 3 trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 882-410295-539.

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. A Phase I/II clinical evaluating the effect of long-acting erythropoietin darboepoietin-alpha in low-risk, anemic MDS. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 882-410295-539.

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. A Phase I/II clinical study on allogenic "conventional" and "mini" (non-myelosuppressive) peripheral blood stem cell transplantation in patients with high risk MDS. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 882-410295-539.

JAPAN

Nippon Medical School, Tokyo. IRB2002-22. Open-label study of the safety and efficacy of Thalidomide in patients with Myelodysplastic Syndrome. Contact: Dr. Kiyoyuki Ogata. Phone: 81-3-3822-2131 (Ext. 6321).

THE NETHERLANDS

Universitaire Ziekenhuis Gasthuiberg, Leuven. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Verhoeft. Phone: 011-32-16-346880.

University of Nijmegen, Nijmegen. AZA PH GL 2003. CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous Azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Dr. P. Muus. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EBMT200502. A prospective 2×2 randomized muticenter study evaluating the role of remission-induction and consolidation chemotherapy prior to allogeneic transplantation and of G-CSF mobilized peripheral blood progenitor cells versus bone marrow stem cells using HLA-identical siblings in patients with Myelodysplastic Syndromes and between 5% and 20% bone marrow blasts. Contact: Prof. Dr. T. de Witte. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EORTC 06011. Intravenous low-dose decitabine versus supportive care in elderly patients with primary MDS (>10% blasts or high-risk cytogenetics), secondary MDS of CMMOL who are not eligible for intensive therapy. Contact: Dr. P. Muus. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EPO 2003. A Phase 2 clinical trial to evaluate the feasibility of treatment with Aranesp in patients with Myelodysplastic Syndrome (MDS). Contact: Prof. Dr. T. de Witte. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EORTC 06013. Idarubicin and Ara-C in combination with Gemtuzumab-Ozogamicin (IAGO) for young untreated patients, without an HLA identical sibling, with high risk MDS or AML developing after a preceding period with MDS during 6 months duration. Contact: Prof. Dr. T de Witte. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EORTC 06023. Randomized Phase II trial with Infliximib (Remicade) in patients with Myelodysplastic Syndrome and a relatively low risk of developing acute leukemia. Contact: Dr. P. Muus. Phone: +31-24-3614762.

THE NORDIC COUNTRIES

Nordic MDS Group. NMDSG02B. Phase II study on maintenance treatment with Azacytidine in patients with advanced MDS and MDS-AML, who have obtained CR with intensive chemotherapy. Contact: Dr. Eva Hellström-Lindberg. Phone: 011-46-85-858-0000.

Nordic MDS Group. NMDSG03A. An open, non-randomized Phase II study on the effects of anemia in MDS quality of life, cardiac function and health care costs. Contact: Herman Nilsson-Ehle. Phone: 011-46-85-858-0000.

Nordic MDS Group. AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous Azacytidine plus best supportive care versus conventional care regimens plus best supportive care for treatment of Myelodysplastic Syndromes. Contact: Dr. Eva Hellström-Lindberg. Phone: 011-46-85-858-0000.

POLAND

Jagiellonian University, Cracow. A randomized trial comparing Antithymocyte Globulin (ATG) and Cyclosporine (CSA) with best supportive care in patients with MDS. Contact: Prof. Aleksander B. Skotnicki, MD. Phone: +48-12-421-3693.

Jagiellonian University, Cracow. Phase I/II study of Thalidomide in low-risk MDS. Contact: Pawel Sledziowski, MD. Phone: +48-12-424-7600.

Jagiellonian University, Cracow. Phase III clinical trial of Amifostine/pentoxifylline/ciprofloxacin/dexamethasone for low-risk MDS. Contact: Janusz Krawczyk, MD. Phone: +48-12-424-7600.

Jagiellonian University, Cracow. Phase I/II study of Arsenic Trioxide in high-risk MDS. Contact: Marcin Sobocinski, MD. Phone: +48-12-424-7600.

SPAIN

Hospital Clinic, Barcelona. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Benet Nomdedeu, MD. Phone: +34 93 227 55 11.

Hospital Son Llatzer, Palma de Mallorca. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Joan Bargay, MD. Phone: +34 871 20 21 38.

Hospital Universitario Del Salamanca, Salamanca. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Consuelo Del Canizo, MD. Phone: +34 923 29 13 84.

An Update:

The MDS Foundation will soon be working with the European Hematology Association's MDS Working Group (EHA) to standardize information on clinical trials in Europe. This will aid physicians and patients in identifying and contacting centers about participating in these trials. We'll keep you up to date!

To submit information on your clinical trials for publication, you can fax 609-298-0590) us at the Foundation. Please include a contact person, a phone number, and if applicable, the trial number.

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.

Please contact us at: 1-800-MDS-0839 (phone) or 609-298-0590 (fax).

Outside the US please call: 609-298-1035.

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

Forum on Quality-of-Life in MDS Patients Held

On October 26th, 2004 we held our first MDS Patient Forum in New York City. This special conference afforded patients the opportunity to listen to guest speakers who are experts in MDS. We were very pleased that Dr. Stephen Nimer from Memorial Sloan-Kettering and Dr. Eric Feldman from Cornell University were our guest speakers on MDS.

Patients from the tri-state area participated in a study group and shared their experiences living with MDS and the quality-of-life issues that they face. They were also given the opportunity to participate in a question and answer session with the medical presenters. The information we develop will be used to educate healthcare professionals about MDS patients' needs in dealing with MDS.

This was the first of many patient symposiums we have planned internationally to be centered around our MDS Centers of Excellence. We will be in Tampa, Florida on November 19th and in Stanford, California on December 13th.

Further developments will be posted on our website or for more information contact the Patient Liaison, Audrey Hassan, at 1-800-MDS-0839.

MDS Educational Resources for Clinicians

The Myelodysplastic Syndromes Pathobiology and Clinical Management
(Basic and Clinical Oncology Series/27)

Edited by:
John M. Bennett
James P. Wilmot Cancer Center of the University of Rochester, Rochester, New York, U.S.A.

May 2002/528 pp., illus., ISBN: 0-8247-0782-6/$165.00
CRC Press. 800-272-7737
When ordering, use code PAO50203

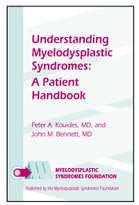
This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse environmental and genetic factors, and efficient modalities of supportive care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

A NEW CME PROGRAM AVAILABLE IN CD-ROM FORMAT

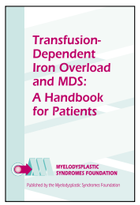
The Myelodysplastic Syndromes: Controversies in Classification and An Optimistic Look at New Treatment Options.

You may request this program by contacting the Foundation at 800-MDS-0839 or by logging on to our website: www.mds-foundation.org.

PATIENT INFORMATION AND EDUCATIONAL MATERIALS AVAILABLE FROM THE MDS FOUNDATION



A.



B.

C.

A. Understanding Myelodysplastic Syndromes: A Patient Handbook
Peter A. Kouides, MD; John M. Bennett, MD

B. Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients
Published by The Myelodysplastic Syndromes Foundation

C. Patient Diary
Published by The MDS Foundation

D. Your Journal: Learning About Myelodysplastic Syndromes (MDS)
Supported by a grant from Celgene Corporation.

Translations available in Spanish, French, Polish, Czech, Japanese, German and Portuguese.

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

The John Peter Murphy Research Fund

A memorial fund has been established by the Myelodysplastic Syndromes Foundation in the name of John Peter Murphy. The Murphy family made a decision to honor their loved one by establishing this fund to be used for research.

Donations have been made by:
David and Barbara Muller, *Cranford, NJ*
Judy and Pete Welker, *Caroga Lake, NY*
Dick and Lois Meyers, *Cranford, NJ*
Kelly and John Kessler, *Westfield, NJ*
Elaine and Roger Klein, *Westfield, NJ*
Patricia Lynch, *Lake Hopatcong, NJ*
Theresa and David Barr, *Branchburg, NJ*
Burton and Nancy Michaels, *Scotch Plains, NJ*
Louis and Nancy Pisciotta, *Bloomfield, NJ*
Donald and Linda Smith, *Paradise, CA*
Frank and Nancy Montalto, *Lindenhurst, NY*
Gloria Kestenbaum, *Teaneck, NJ*
Joseph J. Viglianti & Knowledge Networks, *Cranford, NJ*
Danilo and Maria Pascual, *Cranford, NJ*
Timothy and Nancy Brennan, *West Orange, NJ*
Lawrence and Judith Kantor, *South Orange, NJ*
Jeffrey Callahan and Bederson & Company LLP, *West Orange, NJ*
Joseph and Carol Viglianti, *Mountainside, NJ*
Anny Meyer, *Westfield, NJ*

The MDS Foundation is very grateful for the heartfelt support of the family and friends of John Peter Murphy. Our work as a non-profit organization depends on public funding. If you would like to contribute in this way, or if you have a unique idea of your own, please write to us at PO Box 353, Crosswicks, NJ 08515 or call us at 1-800-MDS-0839.

Patient Services

AirLifeLine: For nearly 25 years, **AirLifeLine** has helped people overcome the obstacle of distance and access to healthcare. Through a nationwide network of 1,500 volunteer pilots, AirLifeLine coordinates *free* air transportation for people in need. AirLifeLine's generous and compassionate volunteer pilots—men and women from all 50 states with a wide variety of backgrounds—donate flights in their personal general aviation aircraft. Passengers fly *totally free*, as often as necessary and for as long as needed, to reach medical care or for numerous other humanitarian needs. Since 1978, and AirLifeLine volunteer pilots have flown over 30,000 missions. In 2002, AirLifeLine volunteer pilots provided free air transportation for nearly 9,500 passengers (men, women, and children), saving them over $4 million in commercial travel expenses, helping them reach medical treatment that would otherwise be inaccessible.

Although the vast majority of its passengers fly for medical reasons, AirLifeLine pilots also offer free flights for other humanitarian reasons. Each summer, AirLifeLine's volunteer pilots distribute the children from Chernobyl to host homes across the U.S. for a two-month summer respite. They also transport hundreds of children to health-related summer camps each year. And, within 48 hours of the terrorist attacks on 9/11/01 and while most aircraft were still grounded, AirLifeLine volunteer pilots were in the air transporting emergency service personnel, disaster victims, blood and medical supplies in support of disaster relief efforts in New York City and Washington, D.C.

AirLifeLine is a non-profit 501 (c) (3) organization that relies 100% on the generosity of volunteer pilots, as well as individual, corporate, and foundation contributions. AirLifeLine is the oldest and largest national volunteer pilot organization in the United States. For more information about AirLifeLine, visit www.AirLifeLine.org or call toll-free (877) AIR LIFE (877-247-5433).

RESOURCE DATABASE INFORMATION:

Agency Name: **AirLifeLine**

National Office
5775 Wayzata Blvd., Suite 700
Minneapolis, MN 55416
Phone: (952) 582-2980
Toll-free: (877) 727-7728
Fax: (952) 546-5885

Call here for: Outreach, development and administrative inquiries.

Operations Center
50 Fullerton Ct.
Suite 200
Sacramento, CA 95825
Phone: (916) 641-7800
Toll-free: (877) AIR LIFE (247-5433)
Fax: (916) 641-0600
Call here for: Passenger/pilot inquiries
TYY: Not available, but we can use a relay operator.
Website: www.AirLifeLine.org
E-mail: Info@AirLifeLine.org
Administrator: Randy Quast, President & Volunteer Pilot

Contact Person for Agency Information:
Ginger Buxa
Director of Outreach
Ginger@AirLifeLine.org
(877) 727-7728

Program Description:
Since 1978, AirLifeLine has helped to ensure equal access to healthcare and improve the quality of life for thousands of people throughout the United States by coordinating free air transportation for those in need.

Services Provided:
AirLifeLine coordinates the following services:

1. Transporting people with medical and financial need to reach medical care far from home.
2. Transporting people with time-critical needs associated with a transplant procedure.
3. Transporting precious cargo such as organs, blood, tissue and medical supplies.
4. Providing free air support for disaster relief efforts in times of crisis.
5. Providing flights for numerous other humanitarian needs.

Funding Source:
AirLifeLine is a national non-profit 501(c)(3), charitable organization funded entirely by tax deductible donations from individuals, foundations and corporations and the generosity of our volunteer pilots who donate the direct costs of every flight. Over 94% of all support and contributions donated to AirLifeLine goes directly to program services.

Volunteer Opportunities:
AirLifeLine is currently seeking volunteer pilots in many areas of the country. For more information, visit www.AirLifeLine.org or call (877) AIR LIFE.

Passenger Eligibility:
Our volunteer pilots fly passengers free of charge and as often as necessary for diagnosis, treatment, and follow-up care, and for other humanitarian reasons.

1. AirLifeLine passengers must be ambulatory or need little or no assistance to board and exit the aircraft.
2. Passengers must be medically stable and able to fly in an unpressurized aircraft.
3. Passengers must demonstrate financial need.

Application Method:
To request a free flight, just call toll-free (877) AIR-LIFE (877-247-5433). In urgent situations, a coordinator can be paged after normal business hours. Just call (877) AIR LIFE and follow the paging instructions on the voice mail message.

You may also request a flight by visiting www.AirLifeLine.org.

Service Area:
All U.S. states, parts of Canada and Mexico.

Cost/Fees: None, but donations accepted.

Waiting List:
None, but 1–2 weeks advance notice is preferred.

Target Group: Anyone with financial need who needs air transportation.

Age Range: All

Handicap Access: Somewhat, depending on type and size of aircraft.

Languages: English and Spanish

If you need more information for your resource database or website listing, please contact:

Ginger Buxa, Director of Outreach
(877) 727-7728, *E-Mail:* Ginger@AirLifeLine.org

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.

The MDS Foundation is grateful for community support. Our work as a non-profit organization depends on public funding.

If you would like to contribute in this way, please write to us at:

36 Front Street, P.O. Box 353
Crosswicks, NJ 08515

or call us at 1-800-MDS-0839.

A Living Endowment donation has been made in honor of:

Lokey Johnson

This donation has been submitted by:
William and Suzanne Johnson, *La Grange, IL*

A Living Endowment donation has been made in honor of:

Albert Nase's 80th Birthday

This donation has been submitted by:
Joann and Richard Vesole, *Bettendorf, IA*
Stanley and Theresa Nase, *Hot Springs, SD*
Ricky Nase, *Brookings, SD*
Michael and Mary Rahe, *Burt, IA*

Suzanne Fleischman Memorial Fund for Patient Advocacy

New donations have been made by:

Edward Fleischman, *Prescott, AZ*

Eugene and Eloise Fox, *Kensington, CA*

In Memorium

A memorial fund has been established in the name of

Mr. George Allen

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

Joan Dillard
Harvard, MA

Angelo and Eleanor Dibella
Sanford, ME

Skillin's Greenhouses
Falmouth, ME

A memorial fund has been established in the name of

Mrs. Jackie Anderson

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

James and Suzanne Greenquist
Alexandria, VA

Marcia Hertsgaard
Denver, CO

Robert and Anneliese Echard
Joppa, MD

Dr. and Mrs. Bennett Porter, Jr.
Eden Prairie, MN

Gerald and Joan Kugel
Sacramento, CA

A memorial fund has been established in the name of

Mrs. Vivien Balick

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

Geoffrey and Sandy Goldworm, *Cherry Hill, NJ*

A memorial fund has been established in the name of

Mr. Robert James Beams

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

James F. Higgins
Freehold, NJ

Kenneth and Lisa Russo
Freehold, NJ

Thomas and Nancy Bibby
Neptune, NJ

Philip and Catherine Vourtsis
Manalapan, NJ

Social and Recreational Committee
Manalapan, NJ

George and Margaret Weber
Manalapan, NJ

United States Postal Service Employees
Lakewood, NJ

Lori Beams
Englishtown, NJ

Kathy Bibby
Freehold, NJ

A memorial fund has been established in the name of

Ms. Julie Bernard

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

Mr. and Mrs. Robert N. Dietz, *Alice, TX*

A memorial fund has been established in the name of

Mr. Raymond Blair

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

Hazel B. Davis
Scarborough, ME

The Times Record
Brunswick, ME

Bruce W. Smith
Cumberland, ME

Virginia M. Wright
Cumberland, ME

Ruth Peck
Topsham, ME

Jerome and Robin Full
Palm Coast, FL

Bryce and Joan Bayer
Brunswick, ME

A memorial fund has been established in the name of

Mr. Roger A. Brown

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

Bud and Mary Alice Thomas
Darien, GA

Anthony and Barbara Cristoforo
Mount Holly, NJ

A memorial fund has been established in the name of

Mr. Ed R. Burlie

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

Ron, Larry, and Jerry Burlie, *Hutchinson, KS*

A memorial fund has been established in the name of

Ms. Phyllis Carter

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

Bonnie Cooper
League City, TX

Taichyi Shei Lai, *Plano, TX*

Robert and Marjorie Rutford
Richardson, TX

A memorial fund has been established in the name of

Mrs. Carol Cazier

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

Claire T. Cazier
Los Angeles, CA

David and Jacqueline Smiley
Corona Del Mar, CA

Edward Cazier
Los Angeles, CA

Bobbie and Patricia Williamson
Corona Del Mar, CA

Robert and Itsuko Kobayashi
Ranch Palos Verdes, CA

Alan and Mary Andrews
Newport Beach, CA

Ralph and Elaine Limhoff
Balboa, CA

Richard Jones
Newport Beach, CA

Charles and Barbara Strodel
Corona Del Mar, CA

Patricia Zorn
Corona Del Mar, CA

Preston and Bonnie Zillgitt
Corona Del Mar, CA

A memorial fund has been established in the name of

Mr. Lawrence Conn

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

Tom and Leola Lovelace,
Coalinga, CA

Evelyn Berman,
Coalinga, CA

Zollie and Mary Nell Knight
Coalinga, CA

Donald and Joan Clark
Tulare, CA

Eugene J. Erner
Carmel, CA

Ranchers Cotton Oil
Clovis, CA

Mike and Debbie Long
Fresno, CA

Michael Long
Fresno, CA

Phil and Joan Laird,
Fresno, CA

C.W. and Natalie Ayers
Coalinga, CA

A memorial fund has been established in the name of

Mr. Edward J. Coyne

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

Donald F. Burke
Brick, NJ

Mary Skidmore
Point Pleasant, NJ

Robert McCabe
Point Pleasant, NJ

Frank and Doris Di Padova
Point Pleasant, NJ

William Michael and Irene Marquis
Brick, NJ

Michael and Kirsten Flattery
Norwalk, CT

A memorial fund has been established in the name of

Mr. Warren Deming

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

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Burlington, KY

Jacqueline Coulombe
Acushnet, MA

Berengere M. Bairos
Acushnet, MA

Mr. and Mrs. Kaiser
Farmington, CT

Patrick and Dominique Coulombe
Barrington, RI

Susan Saffery
Huntington, NY

A memorial fund has been established in the name of

Mr. Ed R. Burlie

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

Ron, Larry, and Jerry Burlie, *Hutchinson, KS*

A memorial fund has been established in the name of

Ms. Phyllis Carter

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

Bonnie Cooper
League City, TX

Taichyi Shei Lai
Plano, TX

Robert and Marjorie Rutford
Richardson, TX

A memorial fund has been established in the name of

Mrs. Mary Lou Eekhoff

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

George and Marilyn Eekhoff, *Belmond, IA*

A memorial fund has been established in the name of

Mr. Sam Friedman

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

William M. Friedman, *Litchfield, CT*

A memorial fund has been established in the name of

Mrs. Jennifer Gallagher-Welch

Donations have been made in Mrs. Gallagher-Welch's memory by:

Carolyn B. Carlson, *Ocala, FL*

A memorial fund has been established in the name of

Mr. Roger D. Griswold

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

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Robert Mullen
Ft. Myers, FL

Marvin and Patricia Griswold
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Clarence and Elizabeth Root
Decatur, AL

Thomas and Katherine Cooper
Vandalia, OH

Hyman Rosenstein
Nesconset, NY

Gregory and Julia Daniels
South Charleston, OH

A memorial fund has been established in the name of

Dr. Joseph Guttfriend

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

Lori A. Hess
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Nancy Livers Margolis
New York, NY

Eileen Livers
New York, NY

Eric and Jeri Alper
Great Neck, NY

Dr. and Mrs. David Edelstein
Great Neck, NY

Burton Cohen
Cliffside Park, NJ

Robert and Phoebe Lewis
Great Neck, NY

Natalie Gordon
Oceanside, NY

A memorial fund has been established in the name of

Mr. Bob Hagen

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

Jan Rowen
Eureka, CA

Bill and Pat Stiles
Pleasant Hill, CA

Judy Malone, *Martinez, CA*

A memorial fund has been established in the name of

Ms. Lorraine Halasiewicz

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

Helen Szymanowski
Cape May, NJ

Alfred Sokalski
Toms River, NJ

Anne Berkery, *Haddonfield, NJ*

A memorial fund has been established in the name of

Mr. Norman Halpern

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

Harold and Joyce Tittleman, *Wayne, PA*

A memorial fund has been established in the name of

Ms. Hazel A. Klueh

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

Charles and Susan Chupack
Farmington Hills, MI

Nick and Stephanie Chupack
Waterford, MI

Benson and Pamela Thomas
Clarkston, MI

A memorial fund has been established in the name of

Mr. John Paul Johnson

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

J. Harold Boyd
Monroe, GA

Lawson and Rose Sewell
Loganville, GA

Neal and Wanda Savage
Grayson, GA

A memorial fund has been established in the name of

Mr. Joseph Kotelnicki

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

Tammy and Michael Kotelnicki, *Vienna, VA*

A memorial fund has been established in the name of

Reverend Lawrence Larsen, Jr.

Donations have been made in Reverend Larsen's memory by:

Jerome and Margaret Grubaugh, *Bainbridge Island, WA*

A memorial fund has been established in the name of

Mr. Charles Lee

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

Christopher and Catherine Engel, *Chatham, NJ*

A memorial fund has been established in the name of

Mrs. Florence Littlejohn

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

William Frank, *San Francisco, CA*

A memorial fund has been established in the name of

Mrs. Sema Maric

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

Lynne O'Brien, *Ontario, Canada*

A memorial fund has been established in the name of

Mr. George Manocchio

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

James and Deborah Horner, *Sylvania, OH*

A memorial fund has been established in the name of

Mrs. Joyce Mashburn

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

Henry and Norma Moody
Newnan, GA

James and Corine Corry
Covington, GA

A memorial fund has been established in the name of

Mr. Jack McCullough

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

Lynn and Kathryn Bendall
Memphis, TN

Highland Heights Presbyterian Church
Cordova, TN

A memorial fund has been established in the name of

Mrs. Barbara Claire Meland

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

Norman and Laura Allison, *Marlton, NJ*

A memorial fund has been established in the name of

Mrs. Virginia Militzer

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

Walter and Josephine Goldstein
Livingston, NJ

Patricia McQuade
Naples, FL

Bernadette F. Gannon
Philadelphia, PA

A memorial fund has been established in the name of

Mrs. Shirley Millard

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

Glenn Millard, *Whitewater, WI*

A memorial fund has been established in the name of

Mrs. Janet Mullikin

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

Knoll
East Greenville, PA

Ed and Ernestine Norton
Brookhaven, MS

A memorial fund has been established in the name of

Mrs. Norma Rolando

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

Angelo R. Rolando
Rocky Hill, CT

Church of St. Elizabeth Seton
Rocky Hill, CT

Robert and Noella Lapierre
Newington, CT

A memorial fund has been established in the name of

Dr. Sierra

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

Tracy Land
Indianapolis, IN

Steve and Kim Rowe
Fishers, IN

A memorial fund has been established in the name of

Mrs. Myrtle W. Slade

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

Jeffrey and Sarah Kowalak
Trinity, TX

Dr. and Mrs. William Garrison
Flat Rock NC

Robert C. Wilson, Sr.
Hendersonville, NC

A memorial fund has been established in the name of

Mr. Michael Stabile

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

Cory and Heidi Ackerman
Westfield, NJ

Eugene and Elizabeth Tozzi
Bridgewater, NJ

Marvin S. Lieberman, Esq.
Somerville, NJ

George and Pat Schofield
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George and Jean Collins
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Frederick and Betty Jane Dudeck
Bridgewater, NJ

John and Mary Dumont
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Lewis and Roberta McDougal
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Wayne and Donna Hogrebe
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Jeffrey Manning
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Howard and Wendy McNeely
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Dr. and Mrs. Allan Tiedrich
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Mindi Forgash
Westfield, NJ

Ms. Joan Strauss *(continued)*

C.A. Granzetto,
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Michael and Marilyn Crisci
Somerville, NJ

A memorial fund has been established in the name of

Ms. Joan Strauss

Donations have been made in Ms. Strauss' memory by:

Tom and Lois Schwab
Holyoke, MA

James Reilly
Sun City Center, FL

Maurice and Florence Bond
Northampton, MA

Alice Shearer
Northampton, MA

Elaine Brennan
Northampton, MA

Peter Haas
Florence, MA

Julie Zuckman
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William and Susan McCoy
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West Springfield, MA

Olde Towne Commons Condominium Association
Northampton, MA

Rita Fogel
Northampton, MA

Carl and Theresa Schmittlein
Naples, FL

Bob and Nancy Kalin
Florence, MA

Ann Henchey
Northampton, MA

Dutche August
Northampton, MA

Morris Goald
Northampton, MA

A memorial fund has been established in the name of

Mr. Michael Stuto

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

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New York, NY

John and Eileen Wimberger
Ramsey, NJ

Carl and Susan Bell
Bettendorf, IA

Daniel and Elaine Bitar
Foxboro, MA

John and Deborah Plocinik
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Theresa Fracchiolla
Jackson Heights, NY

Loretta Necotra
Jackson Heights, NY

Richard and Rose Agosto
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William and Mae Jean Bahrke
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Jeffrey and Eileen Riman
Paramus, NJ

Jennifer Elliott
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Secaucus, NJ

Joan Delfino
Secaucus, NJ

David McWater
New York, NY

Eric Speck
New York, NY

Laura, Johnnie and Jessie c/o Tozzer Ltd.
New York, NY

Cheryl Cavanaugh
Towaco, NJ

Matthew Curtis
New York, NY

Helmut and Lois Boehl
Ogdensburg, NJ

Andrew Mitchell
Atlanta, GA

Lorraine Mazzola
Brooklyn, NY

A memorial fund has been established in the name of

Mr. Richard Valicenti

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

Mr. and Mrs. John Deegan, *Brewster, MA*

A memorial fund has been established in the name of

Mr. Aaron Wegweiser

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

Beatrice Wegweiser, *Plantation, FL*

A memorial fund has been established in the name of

Mr. Russ Woodlief

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

Dean C. Matthews
Rio Verde, AZ

H. Wayne Roberts
Wichita, KS

William and Ethel Epstein
Laguna Woods, CA

T. Carl and Dona Badgett
Houston, TX