



THE MDS NEWS

The Newsletter of The Myelodysplastic Syndromes Foundation

From the Guest Editor's Desk

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Iron Overload in Myelodysplastic Syndromes (MDS) – the Silent Enemy

Recent years have witnessed rapid growth in the understanding of mechanisms that govern the pathophysiology of MDS. Such discoveries have led to the use of many new pharmacologic agents in this

disease, many of which have clear activity. Despite these therapeutic advances, however, supportive care remains a mainstay of treatment for the majority of patients with MDS.

At the core of supportive care is red blood cell transfusion, a treatment that is frequently used to alleviate symptoms and reduce cardiopulmonary burden that result from anemia, ultimately caused by ineffective erythropoiesis in MDS. Each unit of transfused red blood cells contains 200–250 mg of elemental iron. Because net iron excretion in the average adult totals 1–2 mg/day, it is not difficult to appreciate that iron accumulation will occur with repeated transfusions.¹ Ultimately, this accumulation will lead to a syndrome of iron overload, also known as transfusional siderosis, in which iron accumulation and deposition can lead to vital organ failure. Pathologically, this process is similar to what occurs with untreated hereditary hemochromatosis, whereby excess iron becomes deposited in parenchymal cells of the liver, heart, and endocrine organs, leading to eventual failure of these organs.^{1,2} Although the precise quantity of transfusional iron required to cause end-organ damage varies among individuals, iron-removal therapy is ideally begun prior to the serum ferritin exceeding 200 mcg per liter in premenopausal women, or 300 mcg per liter in men and postmenopausal women.² In hereditary hemochromatosis, simple phlebotomies are highly effective in removing excess iron and eliminating the risk for end-organ damage if detected soon enough.² In MDS and other primary blood diseases, phlebotomy is not a therapeutic option due to the presence of underlying ineffective hematopoiesis. Hence, in the absence of definitive therapy that eliminates the need for red blood cell transfusions, the only way to effectively treat and prevent iron overload is through chelation therapy.

Chelation Therapy for Iron Overload Syndromes

Chelation therapy, when administered properly, can be effective in promoting stable or negative iron balance in patients with transfusional siderosis. Most of the data that document efficacy of iron chelation therapy on organ protection and survival emanate

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from patients with B-thalassemia, a hereditary hemoglobinopathy that results in ineffective erythropoiesis.^{3,4} Desferroxamine is a parenterally administered hexadentate compound with a short biological half-life that can prevent iron-induced cardiomyopathy and extend survival in patients with thalassemias.⁵ It is the only iron chelator to date that has clearly demonstrated clinical benefit to patients with iron overload syndromes.^{3,4} However, its inconvenient method of administration via prolonged subcutaneous infusion may lead to a lack of compliance, particularly in elderly patients.⁶ In addition, side effects from desferroxamine such as infection, hearing loss, and visual loss have been described.^{7,8}

The overall clinical efficacy of iron chelation therapy in patients with MDS is largely unknown, in part due to lack of clinical trials in such patients. The paucity of data in MDS may reflect a general hesitancy to institute chelation therapy in many patients, due to other comorbidities, as well as the expectation that patients will die from their disease before clinically significant iron-related injury occurs. This may be especially true in the higher risk MDS subgroups, where survival is often measured on the order of months.⁹ To date, the only published data on the use of iron chelation therapy in MDS patients came from a small study of 11 patients treated with subcutaneous Desferroxamine on a 5 day per week schedule.¹⁰ In this study, 9 of 11 patients had decreased serum ferritin levels with treatment, and MRI-determined liver iron concentration decreased in all patients. Interestingly, there appeared to be an improvement in bone marrow erythroid marrow activity, as determined by a decreased transfusion requirement in the majority of patients as well as an increase in platelet and neutrophil counts, and an increase in the serum transferrin receptor concentration. These findings, while not indicative of a clear effect on prevention of cardiomyopathy or improvement of survival, suggest that iron overload may negatively impact bone marrow erythropoiesis, and that correction of such may improve marrow function.

Oral Iron Chelators

Until recently, the broad implementation of oral iron chelation has been limited by risks of serious side effects and a narrow therapeutic margin. While initial reports of the oral iron chelator Deferiprone suggested a decrease in total body iron concentrations,¹¹ updated results indicated a

possible increased risk for progression of liver fibrosis.¹² To this end, efforts utilizing computer-assisted molecular modeling have been made to develop safer, better tolerated oral chelators. ICL670, a tridentate iron chelator, represents a heretofore successful end result of these efforts. In preclinical models, this agent is highly orally bioavailable, selective for iron, and more potent than desferroxamine.¹³ In humans, it has undergone testing in the setting of B-thalassemia. To date, early phase clinical trials of ICL670 have demonstrated excellent tolerability, net iron excretion, linear pharmacokinetics, and chelation of iron within the plasma.^{14,15} A clinical trial utilizing this agent in MDS has recently been launched.

Conclusions

The therapeutic armamentarium in MDS has grown rapidly in the past few years, with the introduction of exciting new compounds such as immunomodulatory drugs (Lenalidomide), DNA methyltransferase inhibitors (5-azacytidine and Decitabine), and farnesyl transferase inhibitors (Tipifarnib, Lonafarnib). These agents are clearly active in subsets of patients with MDS, and this activity is largely reflected by improvements in hematologic parameters, including transfusion requirements.¹⁶⁻²⁰ Ultimately, the best way to eliminate the risk of transfusional iron overload is to effectively treat the underlying disease with new compounds such as these. However, it is anticipated, at least in the short term, that these novel agents will benefit subsets of patients only for a limited amount of time, until more experience is gained to determine their optimal administration, both alone and in combination. Until then, supportive care with red blood cell transfusions will remain an integral part of the management of MDS. As patients achieve better control of their disease, effective treatment of long-term complications such as transfusional siderosis will be vital to prolonging survival and quality of life, and efforts to develop new strategies to combat these long-term complications must continue in parallel with direct anti-MDS treatment strategies.

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Save the Date: Aug 7, 2006

The Jack Keating Memorial Golf Tournament for MDS

On October 19, 2005 the MDS Foundation lost a great friend, Jack Keating. Jack was one of the driving forces that started the MDS Foundation's annual Golf Tournament that supports The Foundation's Young Investigator Grant Program.

Affectionately called "Six-Pack" by the PGA Professionals and the caddies who were his peers on the PGA Tour, Jack carried Bruce Fleischer's bag for 18 years. A veteran of two tours of duty in Vietnam, Jack returned from the Army and found his home on the PGA tour.

In 2003, Jack introduced The Foundation to Bruce Fleischer and helped us begin this important Tournament in 2004. After two years, the proceeds from this Tournament have funded two, two-year Young Investigator Grants. This important endeavor could not have been completed without Jack's help, his enthusiasm, and his love for other people.

We offer our condolences to Jack's family and will remember Jack each year when we hold **The Jack Keating Memorial Golf Tournament for MDS**.

On August 7th, 2006 come see some of the greatest PGA Champion's Tour Pros Play Olde York's No. 9. at the Olde York Country Club, Old York Road, Chesterfield, NJ. Olde York Country Club, designed by the Gary Player Design Group, is the 10th highest ranked course in the state. Olde York Country Club was awarded the 1999 Best Private Golf Course by The New Jersey Golf Owners Association.

You are cordially invited to be a part of the Gallery for this important charity event. The proceeds from this tournament will be donated to The Young Investigator's Grant Fund for Fellows in Hematology. This fund provides resources to further the research of MDS and hopefully, to one day find a cure.

Interested players and sponsors are invited to contact The MDS Foundation at 1-800-MDS-0839 or visit our website at www.mds-foundation.org.



(Pictured L to R) Bruce Fleischer, Joe Thiesmann, Jack Keating, Jim Palmer, Bob Toski, Bobby Wadkins, Bob Murphy, Tony Perla, Mike Schmidt, Jay Sigel, and Jim Thorpe.

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From the Director's Desk

Kathy Heptinstall, Operating Director

The MDS Foundation

This is the first of a new feature of *The MDS News*—“The Operating Director's Desk”. Through this column, I will try to keep you up-to-date on the Foundation, its programs and progress, throughout the year! I also welcome questions and suggestions from our members and others.

2005 has seen the advent of many exciting advances in MDS research and treatment. Since the inception of the MDS Foundation, we have never seen such high-level interest in these syndromes both inside and outside the hematology and pharmaceutical communities. MDS patients and their families can for the first time, I believe, look to the future with hope—hope stimulated by the innovations in research that provided the first approved treatment for MDS (Vidaza®) and will soon provide additional treatments (Revlimid, Dacogen, Exjade) that will prolong and improve their lives.

A primary goal of the MDS Foundation is promoting MDS education and information for patients, physicians, and the general public. The Foundation has become increasingly active over the last ten years and we have reached farther than ever in 2005.

The Foundation has conducted six Quality-of-Life forums for MDS patients in the United States and the first of a similar series in Europe. This initial European forum was held in Edinburgh, Scotland. These Forums are being used to develop educational information for physicians focused on the issues that are most important to patients living with MDS and helpful information for patients living with this disease.

We have initiated the first ongoing Patient Support Groups for MDS patients and are expanding these throughout the United States. Funding has been obtained to support these ongoing meetings and we are actively recruiting patients to facilitate and participate in these groups. Similar Support Groups will be implemented in Europe in 2006.

The MDS Foundation's 8th International Symposium on MDS was held in Nagasaki, Japan in May of this year. This bi-annual meeting was a great success and featured information on the newest research and treatment options in MDS. Key presentations from this meeting are available on CD-ROM for anyone who is interested. Continuing education credit is available for participants. The 9th International Symposium will be held May 16–19, 2007 in Florence, Italy.

An expansive MDS Awareness Program was initiated in September 2005 and will continue, in a multi-segment format, throughout 2006. If you are interested in participating in this state-of-the-art continuing education program, please join us through the Foundation's website (www.mds-foundation.org) or call 1-800-MDS-0839. New segments will be available bi-monthly and can be completed via our educational website, CD-ROM, or in writing.

The Foundation has participated in the American Society of Hematology (ASH) Annual Meeting for eight consecutive years by hosting our booth for physician attendees and conducting adjunct symposia on Corporate Friday. The 8th adjunct symposium will be presented on December 9, 2005 from 9–11 am in Atlanta, Georgia. These symposia have attracted more than 1,000 participants annually and we believe this year's program will be just as successful. This year's symposium entitled: *The Puzzle of MDS: How Do the Pieces Fit?*, will be chaired by Dr. Alan List, and focus on providing the attendees with information on the accurate diagnosis and classification of MDS patients. This program will attempt to provide physicians with the tools to more accurately match patients to treatments and help to insure the best possible outcomes for these patients. Case presentations will provide a common thread throughout the didactic session. Information will be presented via the most technologically advanced media available to expand the interactive learning experience for participants. Please join us for this fascinating program.

During 2005 the Foundation has, for the second year in a row, participated in the European Society of Hematology's (EHA) Annual Meeting, BIO 2005, and the International Congress on Myeloproliferative Diseases and Myelodysplastic Syndromes that was recently held in Washington, DC.

The International Working Group on MDS Morphology has completed a series of three international meetings. The groundbreaking work of this group will be presented during 2006 through educational programming and peer-review publications.

The Foundation conducted the 2nd Annual MDS Foundation Golf Tournament supporting our Young Investigator Grants. For the first time we will provide two, 2-year grants to support Young Investigators in MDS research. These grants total \$40,000 each (\$20,000 a year for two years). The winners of these grants were chosen from a multitude of extremely high-quality submissions. These grants will be awarded at a special ceremony during the ASH meeting in Atlanta. The deadline for grant applications

for 2006 is June 16. Interested applicants can request information from the Foundation.

In October of 2005, I was privileged to attend a meeting of worldwide Patient Advocacy Groups in Hamburg, Germany. The participating groups represented thalassemia, sickle cell anemia, Diamond-Blackfan, and other rare anemias. The MDS Foundation represented the MDS patient population worldwide.

Following the presentation of information on oral chelation therapy as an option for iron overload, patient participants presented their stories. These stories formed the basis for a discussion that was very enlightening for me given my focus on MDS and our patients.

The experience of patients suffering from these seemingly unrelated- or distantly-related diseases share many common threads: fear of the future, the lack of effective treatment options, transfusion-dependence and the threat of iron overload that accompanies this dependence, and the quality-of-life issues that surround these diseases. Patients with these diseases are primarily treated by red cell transfusions. While red cell transfusions are used for disparate reasons: pain due to oxygen deprivation, lack of sufficient hemoglobin, etc. these patients share common experiences—they are tied to physician visits, hospital visits for transfusions, the threat of transfusion-related side effects including iron overload, and exposure to other diseases (e.g., IV, hepatitis). As MDS patients know, the disease and the supportive care that is required often becomes the focus of their lives.

The group discussed ways that advocates for these different patients could join together to more effectively influence research into these transfusion-dependent diseases and the issues that affect patients. Follow-up information is being developed by the facilitators for this meeting. I will keep you up-to-date on the



Celgene has provided the MDS Foundation with an educational grant to support the Foundation's work.

progress that we make in forming a coalition representing patients suffering from these anemias.

Looking forward to 2006 the Foundation will continue to expand our ongoing programs including the Awareness Program, our 3rd Annual Jack Keating Memorial Golf Tournament for MDS (please see the Memorial to Jack Keating in this issue), attendance at EHA 2006 in Amsterdam, planning and implementation of the 9th International Symposium, ASH 2006, and completion of ongoing programs and publications.

I would like to thank our supporters on behalf of the Foundation and its Board of Directors. These supporters, first and foremost, are the MDS patients, their families and friends, who form the core of this Foundation. You are our center and the reason that the Foundation exists. We work for you.

The second group that we would like to thank are the pharmaceutical companies that provide us with so much support and assistance. This assistance is given in the form of grants that fund programs that are non-product related but, rather, are geared toward improved disease knowledge and patient support. We could not do the work they do without this type of support.

I look forward to conversing with you in 2006 and wish you and your families the safest and happiest of holidays with good wishes for the year to come.

Purchase MDS Awareness Pins

The MDS Foundation has enameled lapel pins for you to wear with pride and to increase public awareness about MDS. The pins are available with a \$3.99 donation to The MDS Foundation.



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

This item was created especially for The MDS Foundation to contribute to the effort to help people worldwide living with myelodysplastic syndromes. Your donation will help increase awareness of this little known disease, which is the most common of the hematologic malignancies.

Please ask your family and friends to wear these pins in support of our mission!

The Foundation Announces New Educational Programs

The MDS Foundation is pleased to announce the following educational initiatives:

MDS Foundation Resource Center

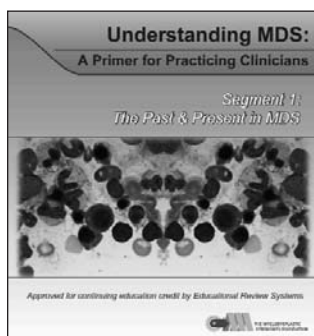
Understanding The Myelodysplastic Syndromes

A New Resource for Healthcare Professionals

This educational center is designed to provide clinicians, researchers, and other healthcare professionals with a comprehensive source for the latest information and educational programming on the myelodysplastic syndromes.

In the Conference section you can view materials presented at MDS conferences or register for upcoming MDS-related symposia.

The MDS Foundation's Awareness Program for 2006 and Beyond



Understanding MDS: A Primer for Practicing Clinicians

Segment 1, The Past & Present in MDS.

This segment introduces the group of bone marrow disorders called MDS and provides a history of myelodysplastic syndromes up to the present time.

This multi-segment program will allow participants to choose the segments that interest them and to learn at their own pace. Segments may be completed via a written program, on-line in our technologically advanced MDS Foundation Educational Center, or via CD-ROM on their personal computer.

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

For information on how to participate in either of these two programs, please contact the MDS Foundation at 1-800-MDS-0839 or visit our website and link to our educational resource center at www.mds-foundation.org.

Foundation Plans International Symposia Through 2011

The MDS Foundation has approved applications for the next three International Symposia. These symposia are scheduled for 2007 in Florence, Italy; 2009 in Patras, Greece; and 2011 in the United Kingdom.



Ninth International Symposium – May 16–19, 2007 Florence, Italy

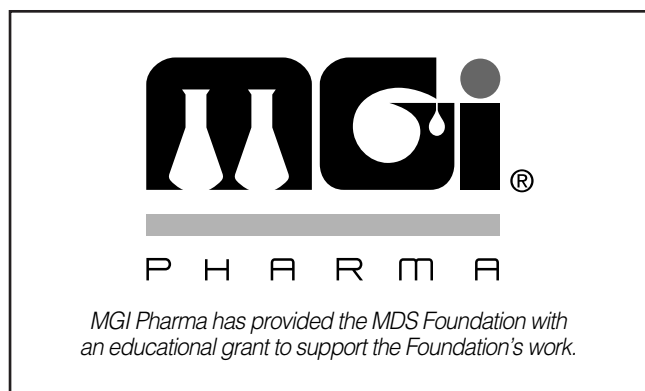
Sponsor: Mario Cazzola, MD

Tenth International Symposium – Spring 2009 Patras, Greece

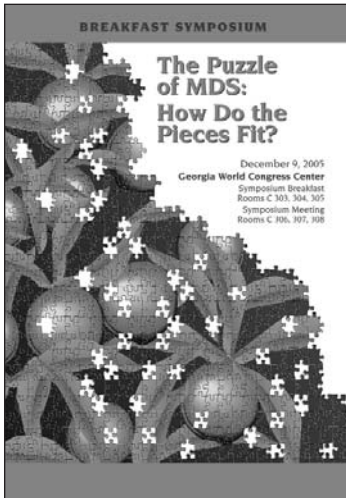
Sponsor: Nicholas C. Zoumbos, MD

Eleventh International Symposium – Spring 2011 United Kingdom

Sponsor: David T. Bowen, MD



2005 Meeting of the American Society of Hematology



Please make sure to visit the MDS Foundation Booth #3236.

3rd International Congress on Myeloproliferative Diseases and MDS

The 3rd International Congress on Myeloproliferative Diseases and Myelodysplastic Syndromes was held on October 27–29, 2005 in Washington, DC. The event was well attended by physicians from across the United States and Europe.

The Chairman of the MDS Foundation, Dr. John Bennett served as Chairman of the session on MDS. The scientific symposium included the following topics:

Event-associated (secondary) myelodysplastic syndromes by John M. Bennett, MD; *Gene methylation in myelodysplastic syndromes* by Steven D. Gore, MD; *What transplant and when for patients with MDS?* by H. Joachim Deeg, MD; *Farnesyl transferase inhibitors* by Eric J. Feldman, MD; and *Hematologic and cytogenetic response to lenalidomide in myelodysplastic syndromes* by Alan F. List, MD. Dr. List also serves as a member of the Foundation's Board of Directors.

MDS Young Investigator's Grant Announcement

We are pleased to announce the initiation of a series of grants for The Young Investigator's Grant Fund for Fellows in Hematology from institutions that form our MDS Centers of Excellence. Two awards will be made this year and subsequent awards will be granted yearly.

The Foundation is dedicated to furthering the research into MDS and invites your Young Investigators (under the age of 40) to submit either basic or clinical research proposals into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis or management of the Myelodysplastic Syndromes.

The application deadline for 2006 is June 15. Notification of the awards will occur by October 1, 2006 with activation on January 1, 2007.

These awards will provide \$40,000 over a 24-month period from January 1, 2007 to December 31, 2008.

The two Young Investigator Grants awarded for 2006 will be announced on December 9, 2005 at a formal awards ceremony to be held in conjunction with the American Society of Hematology's annual meeting in Atlanta, Georgia.



Dr. Alan F. List from H. Lee Moffitt Cancer Center in Tampa, Florida during his presentation.



Oncologic Drugs Advisory Committee

On September 14th the Oncologic Drugs Advisory Committee (ODAC) of the U.S. Food and Drug Administration (FDA) met to review the New Drug Application (NDA) for Revlimid® (lenalidomide) for the treatment of patients with transfusion-dependent anemia due to low- or intermediate-1-risk myelodysplastic syndromes (MDS) associated with a deletion 5q cytogenetic abnormality with or without additional cytogenetic abnormalities. The ODAC Committee voted to recommend approval by a margin of 10–5.

Two MDS patients, Kaete Angel of Redding, Connecticut and Robert Weinberg of Philadelphia, Pennsylvania contacted the Foundation and expressed their desire to participate in this important meeting. They provided insight on the MDS patient's perspective and the effect of MDS on quality-of-life, including transfusion dependence. Without the support and dedication of these individuals we would find it very hard to further the causes of the Foundation and we thank them whole-heartedly for all of their efforts.

Blood Products Advisory Committee and Exjade® Approval

On September 29th, the Blood Products Advisory Committee (BPAC) of the US Food and Drug Administration met to review Exjade. The meeting was open to the public and Otto Szanto, an MDS patient, participated in this extremely important meeting. We are sure that Otto's personal statement about life with MDS had a positive effect on the members of the committee. Otto was joined in this effort by patients suffering from thalassemia and sickle cell anemia among others.

Now, there is good news for the adults and children who are at risk for transfusion-related iron overload. Exjade® (deferasirox), the first and only once-daily oral iron chelator, has been approved by the US Food and Drug Administration. This is a major advance in iron chelation therapy and offers a new alternative to the burdensome continuous infusion therapy.



MDS patient Otto Szanto with his daughter Lisa at BPAC.

Son Raises Funds to Help Mother

Rick Zacks, a native of New Jersey, competed in the Ironman Florida Triathlon on November 5th, a 140.6 mile race that is broken into three parts: a 2.4 mile swim, 112 mile bike ride, and a 26.2 mile run. Rick and his wife Rachel worked tirelessly to prepare pledge packets and to promote awareness for MDS research on behalf of his mother who was diagnosed with MDS.

Following is the letter that Rick and his wife sent out to friends and colleagues:

Dear Friends,

As some of you may know, I ran in the 2003 New York City marathon. My wife and a group of our friends all donned matching "Team Freddie" shirts and followed me around the city as they cheered me on. On the back of those shirts, we had the words "Fighting Myelodysplasia" printed as a tribute to my mother, Joan Mangold who is currently battling this disease.



My mother was diagnosed with MDS in April of 2003. MDS is the name for a collection of disorders in which the bone marrow does not produce enough blood cells. Normally, the bone marrow produces three major types of blood

cells: red blood cells (which carry oxygen to the blood), white blood cells (which help the body fight

infections), and platelets (which help the blood clot). The enclosed leaflet has more information on MDS.

At the time of her diagnosis, Mom's doctor estimated that she would have three to five years to live. As of right now, there is no cure for MDS. Mom started getting periodic blood transfusions to help keep her going and to help her fight the fatigue that turned out to be the major symptom affecting her. Then, in September of 2003, she was selected to be part of a clinical trial for a new drug that was being developed to treat MDS.

The drug seemed to be a success. So much so that Mom was able to plan a cruise to the Caribbean with her children and grandchildren in the summer of 2004. In fact, Mom was feeling so good I convinced her to go parasailing with my wife and me in Cozumel, Mexico. Mom is still participating in the clinical trials, but it seems as if the drug's effectiveness is diminishing. More research is being done and will continue to be done, and this is where you come in. On November 5th, 2005, I will be competing in the Ironman Florida Triathlon. This is a 140.6 mile race that is broken into three parts: a 2.4 mile swim, 112 mile bike ride, and a 26.2 mile run. Yes, that's a full marathon!



I am asking for your pledge to the MDS Foundation to help keep this research going so that a cure might be found. Please fill out the enclosed donation

form and send it along with your check made payable to the MDS Foundation. Please write the word "Ironman" in the memo area so the total dollars can be tracked.

I have also enclosed a self-addressed, stamped post card. I am asking for those making donations to please fill it out with your name and address and send it to me so I can personally thank each and every one after the race.

No pledge is too small...or too big! Every single penny you donate goes directly to the MDS Foundation.

Then, think of me on November 5th, while I compete in the triathlon with my friends, my family, and most importantly, my Mom cheering me on. You can track my progress in real time on ironmanlive.com on race day.

*Thank you so very much,
Rick Zack*

We applaud Rick and his family for their valiant efforts. 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.

Gifts to the Foundation

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

Susan J. Ferber

In memory of Dr. Jerome Ferber, New York, NY

Irène Hartman, Stockholm, Sweden

Joseph Artuso, Ridgefield, CT

Stanley and Ann Trail, De Kalb, IL

Rick and Lynn Clemens, Cedar Creek, TX

Bill and Linda Buckhout, Pacific Grove, CA

Dennis Brooks, San Jose, CA

Steve and Mary Wylong, Baldwinsville, NY

**Joe and Donna Haluscsak,
Olmsted Township, OH**

Timothy Stevenson, Silvis, IL

David Roskin, Brooklyn, NY

William Johnson, Spring, TX

Jason and Michelle Sartori, Silver Spring, MD

Shauna Walcott, Corrales, NM

Joanne Herrmann & Family, Annandale, VA

Patricia Ruckert, Anaheim, CA

Geoffrey and Sandy Goldworm, Cherry Hill, NJ

Sidney and Norma Weinberg, Margate, NJ

Alan and Betty Clark, Morgan Hill, CA

Jim Azevedo, San Jose, CA

The MDS Foundation is very grateful for the heartfelt support of its donors. Our work as a non-profit organization depends on public funding. If you would like to contribute or if you have a unique idea of your own, please write to us at:

36 Front Street, PO Box 353

Crosswicks, NJ 08515

or call us at 1-800-MDS-0839

Share Your Stories

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

A Caregiver's Story

Peet Sööt

My wife, Aldeane Sööt, has survived a bone marrow transplant (BMT) that cured her myelodysplastic syndrome (MDS). Three calendar years—filled with a lifetime of experiences—left me with a desire to share it with you and others who may have to travel a similar path. There were many legs to this journey, from diagnosis to finding a donor, to moving to Seattle for the transplant, to going through the transplant, to recovery at the clinic and to coming home for what turned out to be an extended recovery. Even the extended home recovery consisted of increments when the first taper off of the immune suppressant drug (cyclosporine) was not successful and Aldeane had to sink back into another 9 months of restricted life style. The restricted lifestyle stems from the patient's compromised immune system while taking cyclosporine, requiring that the patient almost develops a sense of paranoia from exposure to infection sources—like the general public.

Given the long journey that we traveled, I have broken it down into segments so that it might be easier for you to follow. These are all macro-elements that are easy to define after the fact. When you are in the middle of the struggle you only focus on making it through the day, or reaching the time for the next meal, or administering the next dose of medicine, or simply seeing the hour hand pass another digit on the dial while you wait for the longed-for improvement.

Diagnosis

Lessons learned by the Caregiver during and after the diagnosis:

- What the word “commitment” means as I applied my mind, body and soul to the task of helping my soul mate through the ordeal of a lifetime,
- how daunting the tasks seem when you have never taken this path before, but how fulfilling it is to

complete the tasks—even if it is a minute task such as preparation of a schedule for taking medicines,

- that I was blessed with parents who insisted on acquiring medical insurance so that finances would not be another stress added to the total picture (even if the insurance costs keep one from having a vacation or other non-essential things in life), and
- how helpless one feels while the local hematologist performs a bone marrow aspiration with only local anesthetic.

This last lesson should never have occurred. After finding that conscious sedation reduces the discomfort of an aspiration to almost nothing, I could only gnash my teeth over the way Aldeane suffered as the local hematologist ground the tool into her hip. My failing is that I have never contacted the local doctor to enlighten him that there is a better way of performing this procedure rather than the medieval approach he took.

Even the bone marrow aspirations at the clinic were a learning experience. I wonder why all the technicians don't know that two fenatyl “lollipops” will generally cause nausea for the patient? Administering the same drug intravenously seldom causes the same effect. That is a frustrating lesson to learn, especially knowing how much Aldeane hated to have emetic episodes (that is much too nice of a term to use for throwing up).

During this phase, Aldeane also had a psychological struggle with the illness that had been presented to her. All her life she had prepared herself for breast cancer, especially since her mother and grandmother had encountered that disease. Since it was such a shock to get a different serious illness, she was able to play a mind game by denying to herself that MDS was “cancer”. As Caregiver, I did not feel it was my job to throw this in her face. I even found corroboration on the internet that MDS is not cancer. It was not necessary to determine if this was absolutely true, I let her try and cope in whatever way she felt that she could be in control. It was not until we were at the transplant clinic that a doctor confronted her with the question of why she was at a cancer center if she did not have cancer. To this day, I am not sure whether or not MDS (especially in its early stages) is cancer or not. Uncontrolled it can turn into Leukemia, but our bodies are continually controlling trace amounts of “cancerous” cells so when does it become “cancer” as a diagnosed disease? Fortunately, by the time this incident with the doctor happened, Aldeane was able to cope with the use of that word.

Searching for a Donor

Finding that Aldeane's lone sibling provided a "perfect" HLA match saved us the agony that you may have to encounter. We were blessed with an immediate solution so we did not have to sit around and wait through the endless rejections. You will have to find another source to help you through that leg of the journey.

The Transplant

Lessons learned by the Caregiver while the patient is undergoing the chemotherapy that kills off all of her bone marrow and then receives the life-giving stem cells from her donor:

- That tears help wash away the tension as you watch helplessly while your beloved is in pain and agony,
- how frustration sets in as doctors or nurses do not accept your observations of how to best help the patient,
- how elated one can be when blood test results show the engraftment of the stem cell transplant, or even the delight of seeing subsequent small improvements in blood counts,
- how despondent one can be when you can't convince the patient to have a positive attitude at all times. (Aldeane generally had a great attitude, but there were times when nothing I could say would help her get back to a positive outlook.)
- how to apply mechanical skills for the patient's comfort in the hospital (by building a framework that would hold the tube that delivered humidified air from the wall outlet to Aldeane's face without her having to wear an irritating mask while she had to breath through her mouth for hours),
- that nurses can teach the patient things that are not in the text books, like how to swallow pills correctly by keeping the chin down and to the side and not throwing the head back while trying to swallow, or how to use a pillow to keep the blanket from putting pressure on the patient's toes,
- that it is faster to push the patient to X-Ray and other hospital labs than waiting for the transportation personnel to show up,
- how to use computer skills to develop spreadsheets that helped to monitor the progress and some times even to forecast when things would happen,
- how to use engineering skills to analyze the medical data, and

- that the amazing human body can withstand full-strength chemotherapy, a serious viral infection, fluid in the lungs, congestive heart failure and poorly administered (including overdoses) of medications and still walk out of the hospital cured from MDS.

Although I grouped all of this in one segment, it really consists of two stages. The initial chemotherapy was administered as an outpatient service in the clinic. Only the last industrial-strength chemotherapy was provided in the hospital. If you encounter this same approach at your facility, double-check that there will be a smooth transition between the two facilities. It was very disconcerting when we showed up at the hospital, only to be chided for being 45 minutes late and that they couldn't find Aldeane's chart—the one that showed her to be terrified of nausea. It is hard to stay calm when you are playing catch-up from the start. We had been told at the clinic that it was no big deal what time we showed up. Wrong! Show up early so you can maintain a sense of control—however little that control actually is.

I encourage you to find out where things are in the hospital. When the patient needs a warm blanket because she is shivering is not the time to wait and see how soon the nurse will respond to a push of the button by the bed. I could have Aldeane covered in a pre-heated blanket in less than a minute by going to get it myself—after I found out where they were stored.

Ask questions about other hospital services. Is there a shower where the live-in caregiver can clean up? Do they have a washing machine that the live-in caregiver can use? Where is the cafeteria and what are its hours? Is there a snack bar where you can get the patient (or yourself) a quick snack? You may or may not be able to live in the hospital room as I did, but there is no stupid question.

While in the hospital make notes about questions to ask the doctors when they make their rounds. They are in the patient's room for such a short time; you will forget what you wanted to ask without notes. Also, take notes of their observations (it is amazing how much you forget and often the patient is not able to help remember).

Keep track of the medications that are to be given to the patient. Nurses are human; they can make mistakes—especially when they would prefer to be home in bed rather than working the graveyard shift.

This leg of our journey took 10 weeks. We moved to Seattle, from our home in Lake Oswego, Oregon, on November 1, 2002. That month was used to settle in,

have the donor visit for final testing and generally prepare for the transplant. There was about a week for outpatient chemotherapy and then admittance to the hospital for the final chemotherapy and the transplant on November 27. The transplant, engraftment and initial recovery only took 4 weeks, so we went back to the condo on Christmas Day. But, Aldeane contracted an infection within a week and we were back at the hospital on New Year's Day. She had to spend another three weeks in the hospital recovering from that infection. This was our experience and may not be what you will encounter. Some people were out of the hospital in a fraction of the time.

Recovery as an Outpatient at the Clinic

Lessons learned by the Caregiver while the patient is recovering as an outpatient:

- That there is little personal time when you need to sanitize the living quarters, prepare meals, do the laundry and help the patient with medicine and personal hygiene,
- that helping the recovering patient take a bath can be an evening's enterprise,
- how a clothes dryer is a great towel heater for a patient coming out of the shower,
- that handling and sterilizing the Hickman catheter is not as daunting as you might fear (and even a squeamish person can give injections when it is necessary),
- that the patient can become superwoman (by being able to climb stairs to our 11th floor condo) if that is what will get her home from the clinic, and
- that organizing, preparing and administering 20 doses of medications per day, some intravenously, is not a trivial exercise.

I may have taken things to the extreme, but I took the sanitizing instructions to heart. Even when we first moved into the condo in Seattle, I had removed everything from the kitchen shelves before wiping the cabinets with a bleach solution. I used a squeegee after every shower so that there would be no risk of letting mold grow. (I have continued this practice to the present day—even for my own showers. It is time consuming, but it keeps the shower nice and clean.) This may be more than necessary but who is to say if a less guarded approach may not yield a life-threatening infection.

To this day I can't understand how other patients risk their recovery by not being "compliant". I shiver when

I read about patients who go out to restaurants while being immune-suppressed just before the transplant.

We were on our way home by March 1, 2003, after having spent about 6 weeks recovering as an outpatient of the clinic.

Recovery at Home

Lessons learned by the Caregiver while the patient is recovering at home:

- That life is still lived a day at a time,
- that one's memory is not very good: as I did not remember being told that the recovery may take years when we were first being briefed about the transplant,
- that tracking over 800 medical claims would have been overwhelming without a computer spreadsheet, and
- that leaving for a business trip allows the patient to forget the warnings of working in the garden long enough for her to contract a fungal infection.

This last lesson is very hard. The caregiver can never have the luxury of saying "I told you so". The patient knows full well that they did something wrong; it does no good for the caregiver to pummel them with the obvious. As I administered anti-fungal medicines for several months after Aldeane worked in the garden for just a few hours (exposing herself to fungi) I had to resist saying "What were you thinking?" We were on this voyage together, we had to work together and not let personal annoyances distract us from the common goal.

Conclusion

Lessons learned by the Caregiver after having lived through this 3-year journey:

- That new illnesses yield a sense of déjà vu as one is fearful that skin rashes are a sign of graft vs. host disease, and
- most of all, how to give glory to God for the opportunity to live through such an event so that I could partially understand how some people suffer in this world, but how He is compassionate in all things.

These are some of the lessons I learned over a three-year period from diagnosis, to transplant, through to full recovery. Some people have it easier; some do not achieve the final goal. Having been blessed with a positive result in our situation, it is now incumbent on me to help you as best as I can with your challenge. There is much more to tell, but your eyes have likely glazed over already. I look forward to the opportunity

of being more help to you. Please contact me through Aldeane's web site (peet@mdssurvivor.com) and ask me questions you may have regarding the challenges that lie ahead of you. I may not be able to answer right away (as trying to get our business back on track after the 3-year distraction seems to fill my time) but I will do what I can to try and make your journey a little easier.



Peet Sööt and MDS survivor Aldeane Sööt

A Patient's Journal

Elizabeth Hickey's BMT Journal About Her Stay at H. Lee Moffitt Cancer Center & Research

Everyone's experiences with MDS and AML combined are different. I hope my experience might help those dealing with these two diseases.

Elizabeth Ann Hickey
Born October 31, 1937
Weight 140 pounds

I love golf (played three times per week), bridge, reading, and movies. I always meant to exercise but had many excuses not to complete my plans. However, I am in good shape. I had breast cancer six years ago – double mastectomy. No radiation or chemo and had a knee replacement ten years ago. All was fine until MDS showed up!

Nine months ago, I was put into the hospital for chest pains. By then my blood work was way out of whack. I did get a physical yearly, but my doctor did not see anything wrong and so I did not. MDS is difficult to diagnose.

I had my first bone marrow test around June 4, 2004. It showed RARS bars. My blasts were 5%. I was put on Procrit at 30,600 units per week. As time passed, my white blood count got so low; I was put on a daily shot of Neupogen.

On July 27, 2004, I visited Mayo where, once again, I had the bone marrow biopsy. My blasts were still at 5% (borderline at this point). He was hoping I could wait for Revlimid, which sounded very promising. Vidaza had just been approved but was not for me. So I waited. I then made an appointment at Moffitt where I was told I was not, at this time, a candidate for Revlimid. I began to worry, although I felt fine. (Take care of yourself.)

So, once again, with very low platelets, I made an appointment at Moffitt for another bone marrow test. Now my blasts went to 60% and I had progressed to AML. I was now a candidate for a bone marrow transplant.

I am now at Moffitt Cancer Center. The best care I have ever had. I believe I have some hints that might help others no matter which hospital one chooses.

- Always keep copies of your blood work etc., and put it in a notebook.
- Add to that copies of all medicines you take and have your own records for the doctors. I made extra copies of my medical history as well. This is easier to do as a handout so you don't forget one.
- If you see a high or low indicated in your blood work, ask questions.
- Get second opinions.
- Keep your spirits up. Attitude is very important. Sometimes it's easier said than done! Work on it!!
- Don't be surprised if you have to have more than one session of chemotherapy to get into remission. It seems to be common although you can make it in one.
- I found DVD movies very helpful in passing the time. So when I was asked, I ordered a DVD. Books on tape are also good.
- You are not allowed to have flowers. The computer is also good for games if you so enjoy. Shalart and Gingurzle were best for me.
- Things all start to taste the same after chemo. Everything has to be well done.

Hospital Stay

Do Bring:

1. Attitude!!
2. Slip on slippers or thongs.
3. Underwear.
4. Sweats – Top and bottom. I felt better dressing every day while I could. Lightweight PJs for both sexes with button-up fronts. Most gowns in hospitals are not comfortable and one's fanny hangs out! At Moffitt, the gowns are the same for males and females.
5. Turtlenecks and light pants are good also.
6. Laundry is a problem here so my sister got to be the laundress.
7. Vaseline. My elbows got sore.
8. pH–One may not use applicator but I rubbed this on from the first day and I have no soreness. Diarrhea can be a problem. You must run all this by the pharmacist but mine thought it was a good thing.
9. Bottles of Purell for keeping hands clean.
10. Hair loss about 10–14 days after chemo seems to be common. When it starts, get a buzz, better than your hair on the pillow. I wear soft baseball caps and add flowers in front. Men would probably like a plain one. Your head will get cold at night and even in the day so my sister ordered, online at Target, cashmere pull-down hats. They are great and are around \$16.00 each. Men, they only come in pink, but maybe you are used to short locks.
11. Cut nails very short. They get dirty very easily. They will grow back.
12. Shaving can only be done with an electric razor for both men and women. With low platelets, etc., they are fearful of cuts that could bleed.
13. In Moffitt, they do not want you to wear wigs. Get them made before so when you go home, you are ready.

Do Not Bring:

1. *Electric toothbrush.* Only soft brushes are used. Your mouth can get sore. Ask for sodium chloride irrigation. You probably will get it. Gargle four times or so daily. Helps greatly with mouth sores that may or may not develop. I came in with gum disease. There is no flossing. I was given chlorhexidine gluconate to keep down the bacteria. Very helpful!

2. *Vitamins (except Centrum Silver–no iron).* They are nervous about Ceruo interference. They will give you your necessary meds and you can take Centrum.
3. *Nightgowns.* They are difficult to pull up to get to your Hickman port.

Hickman Port

This is put in above the breast and mine has three utters (my name). It is painless and best of all no more shots for blood, chemo, etc. It heals rapidly and one is hardly conscious of it after awhile. This is one reason a top that opens is easier, also, for your vitals taken often (blood pressure, pulse, and temperature).

I will let you know more when I have my transplant.

I will make it!

Postnote: We are happy to announce that Elizabeth Hickey is over 120 days post transplant and is doing remarkably well.

Now Available through The MDS Foundation

This MDS White Paper discusses comparative data and the potential clinical benefits of treatments that are either approved by the U.S. FDA or the EMEA or are under consideration by these bodies. This paper and a subsequent peer-review manuscript will hopefully assist physicians in matching patients with treatment. Coupled with the Foundation's other endeavors we hope to impact the care that is available to patients around the world.

To download your free pdf copy, visit our website www.mds-foundation.org or, if you prefer, call 800-MDS-0839 to request a hard copy.



The logo for Genzyme, featuring the word "genzyme" in a lowercase, sans-serif font. The letters are black and have a slightly irregular, hand-drawn appearance.

Genzyme has provided the MDS Foundation with an educational grant to support the Foundation's work.

MDS Foundation Initiatives for 2006 and Beyond

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:

- MDS Practice and Treatment Survey
- The International Working Group on MDS Morphology
- MDS Patients' Quality-of-Life Forums
- Transfusion Burden Registry
- The Working Group on MDS Cytogenetics


■ ADOPT Registry: ATG Dose, Outcomes, and Patient Identification


- Centers of Excellence Patient Support Groups



- CME Awareness Program for 2006

Translations available in Spanish, French, Italian, German and Japanese.



- *The MDS News 2006*  Schering-Plough

- The Young Investigator Grant Program
Supported by The Jack Keating Memorial Golf Tournament

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- Jack Keating Memorial Golf Tournament for MDS
August 7, 2006

Supported by Future Grants

- 9th International MDS Symposium,
Florence, Italy: May 16–19, 2007



Patient Support Groups To Be Established by The MDS Foundation

The MDS Foundation has been working to develop a strategy for setting up patient groups nationwide and assistance is now available to organize support groups for MDS patients. Within the next several months, we will be establishing support groups in the following cities:

- Albuquerque, New Mexico
- Austin, Texas
- New York, New York
- Palo Alto, California
- Philadelphia, Pennsylvania
- Portland, Oregon
- St. Louis, Missouri
- Scottsdale, Arizona
- Seattle, Washington
- Tampa, Florida

The purpose of these groups is to exchange information and resources, to provide comfort and support to patients and caregivers, and to explore the challenges of living with myelodysplastic syndromes.

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

Any member of the Foundation, patients, friends, family members, and caregivers are invited to join. Further developments will be posted on our website. To join these groups or to suggest other locations, please contact Audrey Hassan our Patient Liaison at 1-800-MDS-0839.



MDS Centers of Excellence

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

- An established university (or equivalent) program
 - Recognized morphologic expertise in MDS
 - Available cytogenetics and/or molecular genetics
 - Ongoing research, including Institutional Review
 - Board-approved clinical trials
 - Documentation of peer-reviewed publications in the field
 - The ability and intention to register patients in the MDS International Registry database
- Please contact the Foundation for further information and an application form for your center.*

The following centers have qualified as MDS Centers of Excellence:

UNITED STATES

Albert Einstein College of Medicine Cancer Center

Bronx, New York
Amit Verma, MD

Barbara Ann Karmanos Cancer Institute Wayne State University

Detroit, Michigan
Charles A. Schiffer, MD

The Cancer Center of Hackensack University Medical Center

Hackensack, New Jersey
Stuart Goldberg, MD
Charles S. Hesdorffer, MD

Cedars-Sinai Medical Center UCLA School of Medicine

Los Angeles, California
H. Phillip Koefler, MD

City of Hope National Medical Center

Duarte, California
Stephen J. Forman, MD

Cleveland Clinic Foundation Taussig Cancer Center

Cleveland, Ohio
Jaroslav Maciejewski, MD, PhD

Dana-Farber Cancer Institute

Boston, Massachusetts
Richard M. Stone, MD

Duke University

Duke University Medical Center

Durham, North Carolina
Carlos M. deCastro, MD

Fred Hutchinson Cancer Research Center

Seattle, Washington
Joachim Deeg, MD

Georgetown University Hospital

Lombardi Comprehensive Cancer Center

Washington, DC
Ekatherine Asatiani, MD

Indiana University

Indiana University Medical Center

Indianapolis, Indiana
Larry Cripe, MD

Johns Hopkins Oncology Center

Johns Hopkins Institutions
Baltimore, Maryland
Steven D. Gore, MD

Mayo Clinic

Phoenix, Arizona
James L. Slack, MD

Mayo Clinic

Jacksonville, Florida
Alvaro Moreno-Aspitia, MD

Mayo Clinic

Rochester, Minnesota
David P. Steensma, MD

MCP Hahnemann University

Philadelphia, Pennsylvania

Medical College of Wisconsin Bone Marrow Transplant Program

Milwaukee, Wisconsin
David H. Vesole, MD, PhD, FACP

Memorial Sloan-Kettering Cancer Center

New York, New York
Stephen D. Nimer, MD

Mount Sinai School of Medicine

New York, New York
Lewis R. Silverman, MD

National Heart, Lung, and Blood Institute

Bethesda, Maryland
Elaine Sloand, MD

New York Medical College/ Westchester Medical Center

Zalmen A. Arlin Cancer Center

Valhalla, New York
Karen Seiter, MD

New York University School of Medicine

North Shore University Hospital

Manhasset, New York
Steven L. Allen, MD

Oregon Cancer Center at

Oregon Health & Science University

Portland, Oregon
Peter T. Curtin, MD

Roswell Park Cancer Center

Buffalo, New York
Maria R. Baer, MD

Rush Cancer Institute

Rush-Presbyterian-St. Luke's Medical Center

Chicago, Illinois

Seattle Cancer Care Alliance

University of Washington

Seattle, Washington
John A. Thompson, MD

Southwest Regional Cancer Center

Austin, Texas
Richard Helmer, III, MD

Stanford University

Stanford University Medical Center

Stanford, California
Peter L. Greenberg, MD

St. Jude Children's Research Hospital

Memphis, Tennessee
Gregory Hale, MD

Thomas Jefferson University

Kimmel Cancer Center

Philadelphia, Pennsylvania
Emmanuel C. Besa, MD

Tufts University School of Medicine

New England Medical Center

Boston, Massachusetts
Geoffrey Chan, MD

University of Alabama at Birmingham Comprehensive Cancer Center

Birmingham, Alabama
Peter Emanuel, MD

University of Arizona

Arizona Cancer Center

Tucson, Arizona
Daruka Mahadevan, MD, PhD

University of Chicago

University of Chicago Medical Center

Chicago, Illinois
Richard A. Larson, MD

University of Nebraska

University of Nebraska Medical Center

Omaha, Nebraska
Lori Maness, MD

University of New Mexico

Health Sciences Center

Albuquerque, New Mexico
Robert Hromas, MD

University of Pennsylvania

University of Pennsylvania Cancer Center

Philadelphia, Pennsylvania
Selina Luger, MD

University of Rochester

University of Rochester Cancer Center

Rochester, New York
John M. Bennett, MD

University of South Florida

H. Lee Moffitt Cancer Center and Research Institute

Tampa, Florida
Alan F. List, MD

University of Texas

MD Anderson Cancer Center

Houston, Texas
Elihu H. Estey, MD

University of Texas

Southwestern Medical School

Dallas, Texas
Simrit Parmar, MD

University of Wisconsin, Madison Medical School

Madison, Wisconsin
Mark B. Juckett, MD

Wake Forest University School of Medicine

Comprehensive Cancer Center

Winston-Salem, North Carolina
Istvan Molnar, MD

Washington University School of Medicine

Siteman Cancer Center

St. Louis, Missouri
John F. DiPersio, MD, PhD

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

The Western Pennsylvania Cancer Institute
Pittsburgh, Pennsylvania
Richard K. Shaddock, MD

William Beaumont Hospital Cancer Center
Royal Oak, Michigan
Ishmael Jaiyesimi, MD

OUTSIDE THE UNITED STATES

A.C. Camargo Hospital–Cancer Center
São Paulo, Brazil
Luiz Fernando Lopes, MD, PhD

**Academic Hospital,
Free University Amsterdam**
Amsterdam, The Netherlands
G.J. Ossenkoppelle, MD, PhD

Ankara University School of Medicine Hospital
Ankara, Turkey
Osman Ilhan, MD

AZ Sint-Jan AV
Brugge, Belgium
Dominik Selleslag, MD

Casa Sollievo della Sofferenza Hospital
San Giovanni Rotondo, Italy
Pelligrino Musto, MD

Fundeni Clinical Institute
Bucharest, Romania
Radu Gologan, MD, PhD

**Hannover Medical School
Medizinische Hochschule Hannover**
Hannover, Germany
Prof. Dr. Arnold Ganser

**Heinrich-Heine University Düsseldorf
University Hospital**
Düsseldorf, Germany
Ulrich Germing, MD

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

**Hôpital Claude Huriez, CHU Lille
Service des Maladies du Sang**
Lille, France
Bruno Quesnel, MD

Hôpital Cochin/University Paris V
Paris, France
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Hôpital Saint Louis/University Paris VII
Paris, France
Prof. Christine Chomienne

Hospital de Santa Maria
Lisbon, Portugal
João F. Lacerda, MD

Hospital Universitario de Salamanca
Salamanca, Spain
Prof. Jesus F. San Miguel

Hospital Universitario La Fe
Valencia, Spain
Miguel A. Sanz, MD, PhD

Institute of Hematology and Blood Transfusion
Prague, Czech Republic
Jaroslav Cermák, MD, PhD

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Collegium Medicum**
Krakow, Poland
Aleksander Skotnicki, MD, PhD

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Frankfurt Main, Germany
Johannes Atta, MD

**Karolinska Institute
Huddinge University Hospital**
Stockholm, Sweden
Eva Hellström-Lindberg, MD, PhD

King Chulalongkorn Memorial Hospital
Pathumwan, Bangkok, Thailand
Tanin Intragumtornchai, MD

**King Faisal Specialist Hospital
& Research Centre**
Riyadh, Saudi Arabia
Mahmoud Deeb Aljurf, MD, MPH

**King's College Hospital
Guy's Kings Thomas School of Medicine**
London, England
Prof. Ghulam J. Mufti

Kyoto University Hospital
Kyoto, Japan
Takashi Uchiyama, MD

**Leeds General Infirmary
The Leeds Teaching Hospitals**
Leeds, Scotland
David T. Bowen, MD

**MLL Munich Leukemia Laboratory
Ludwig Maximilians Universität**
Munich, Germany
Torsten Haferlach, MD

**Nagasaki University Hospital
School of Medicine
Atomic Bomb Disease Institute**
Nagasaki City, Japan
Prof. Masao Tomonaga

Nippon Medical School
Tokyo, Japan
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**Odense University Hospital
The University of Southern Denmark**
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Patras, Greece
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Groote Schuur Hospital**
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Heidelberg, Germany
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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.

MDS CLINICAL TRIALS ANNOUNCEMENT

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 Syndromes, 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.

MethylGene Inc., of Montreal, initiated the first of two dose-escalating Phase I trials for MGCD0103 in hematological cancers. MGCD0103 is a rationally designed isotypic selective small-molecule inhibitor of histone deacetylase. The second hematologic cancer trial is scheduled to be initiated in early 2005. Both trials will evaluate the safety, pharmacokinetics, pharmacodynamics and tolerability of MGCD0103 in patients with leukemias or myelodysplastic syndromes.

Novartis. EXJADE Trial C1CL670AUS02. An open label, safety and tolerability study of deferasirox for treatment of transfusional iron overload in low-risk and INT-1 myelodysplastic patients. Thirty patients will be enrolled into this open-label, single-arm trial designed to assess the safety and tolerability of oral deferasirox in adult transfusion dependent myelodysplastic syndromes (MDS) patients with iron overload. Patients enrolled in this study will have low or intermediate (INT-1) risk MDS per International Prognostic Scoring System (IPSS) criteria. All patients will initiate treatment with 20 mg/kg/day deferasirox. Deferasirox will be administered orally once per day for 12 months.

Novartis. EXJADE Trial C1CL670AUS03. An Open Label, Safety and Tolerability Study of Deferasirox for Treatment of Transfusional Iron Overload in Low-risk and INT-1, Myelodysplastic Patients using Serum Ferritin Monitoring. This trial is being conducted to assess safety and tolerability of an investigational drug in patients with low or intermediate (INT-1) risk Myelodysplastic Syndromes and are iron overloaded. This investigational drug removes excess iron from the body. All patients who are eligible to

participate in this clinical trial will receive treatment with deferasirox which is administered orally once per day for 12 months. For further information please contact 800-340-6843 or visit www.clinicaltrials.gov—in the search area, enter Exjade and Myelodysplastic Syndromes.

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.

Novartis. An Open-label Phase II Trial of PKC412 Monotherapy in Patients with Acute Myeloid Leukemia and Patients with Myelodysplastic Syndromes 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.

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).

Schering-Plough Research Institute. P02978. A Pivotal Randomized Study of Lonafarnib (SCH 66336) Versus Placebo in the Treatment of Subjects With Myelodysplastic Syndromes (MDS) or Chronic Myelomonocytic Leukemia (CMML) Who Are Platelet Transfusion Dependent With or Without Anemia. The purpose of this study is to determine clinical benefit of Lonafarnib plus best supportive care versus placebo plus best supportive care, measured as achievement of platelet transfusion independence. This Phase III trial will be conducted at approximately 60 sites in US, Canada, Europe, Latin America, Far East. Contact: Sabine Loechner, e-mail: sabine.loechner@spcorp.com; or Mary Sugrue, MD, e-mail: mary.sugrue@spcorp.com.

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

Contact www.clinicaltrials.gov to learn more about other trials for Myelodysplastic Syndromes. Type in “myelodysplastic syndromes” in “Search Clinical Trials” then click on the “Search” button to obtain a listing.

Other U.S. Trials

Barbara Ann Karmanos Cancer Institute, Detroit, MI. D-696. Allogeneic and syngeneic 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 Syndromes and Acute Myeloid Leukemia, Myelodysplastic Syndromes, 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, MD. Phone: 216-368-5693.

Case Western Reserve University, Cleveland, OH. CWRU-6Y01. This is a phase I trial using umbilical cord blood to evaluate the efficacy of allogeneic transplantation to treat myelodysplastic syndromes or severe aplastic anemia. The rationale for this study is to investigate whether transplantation of more than one UCB unit is safe and whether this approach may overcome the current problems of primary graft failure and delayed engraftment with single unit UCB. This concept will be evaluated in the setting of non-myeloablative conditioning in attempt to decrease the risk of mortality in the event of primary graft failure. Eligible patients must have hematologic cancer including MDS or severe aplastic anemia requiring allogeneic transplantation. Contact Mary J. Laughlin, MD. Phone: 216-368-5693.

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, (Zemlar) 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.

Cleveland Clinic Foundation, Cleveland, OH. IRB #7631. A Study of Darbepoetin Alfa in Anemic Subjects with Low Risk Myelodysplastic Syndromes. This study uses a novel therapeutic, darbepoetin alpha, to promote proliferation of the few remaining normal erythrocyte precursors in the bone marrows of patients with MDS. Objectives include evaluating the efficacy of the drug (as measured by erythroid response) in patients with the more indolent form of MDS, with goals of demonstrating improvement of red blood cell transfusion needs, increase in hemoglobin concentration, and improvement in quality of life. Patients will be given this subcutaneous injection once every 21 days, or once every 14 days if a patient does not show a response to the every-three-week regimen. Patients will continue to receive medication for up to 52 weeks. Previous Phase II studies in patients with other cancers have demonstrated improvement in hemoglobin using a similar dosing regimen, and previous studies in patients with MDS using recombinant humanized erythropoietin (rHuEPO) has demonstrated the ability of a similar growth factor to bring about response rates of 15–20%. By participating in this national, multi-center Phase 2 trial, we hope to be part of what could be a new treatment paradigm for MDS. Contact: Mikkael Sekeres, MD. Phone: 216-445-9353.

Comprehensive Cancer Center of Wake Forest University, Winston-Salem, NC. Phase II Study of Arsenic Trioxide and Dose-Escalated Cholecalciferol in Myelodysplastic Syndromes (CCCWFU 29304). Contact: Istvan Molnar, MD. Phone: 336-716-5847.

Comprehensive Cancer Center of Wake Forest University, Winston-Salem, NC. CCCWFU-29203. Orthomolecular Vitamin D in Low-Risk Myelodysplastic Syndromes: 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.

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 Rizzio03@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 Syndromes. 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 Cytosan (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.

Georgetown University Medical Center, Lombardi Cancer Center, Washington, DC. 05-064. CALGB: Phase II oral VegF receptor/TKI for MDS high-risk disease. Contact: Jenny Crawford. Phone: 202-687-0893.

Georgetown University Medical Center, Lombardi Cancer Center, Washington, DC. 02053. Gene expression profiling in myelodysplastic syndromes (collection of bone marrow aspirate is needed). Contact: Ekatherine Asatiani, MD. Phone: 202-444-3958.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 14454. An open-label, safety and tolerability study of deferasirox for treatment of transfusional iron overload in low risk and intermediate-1 MDS patients using serum ferritin monitoring. Pending. Contact: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 14185. Phase I study of KOS-1022 for injection (DMAG-HCL) administered intravenously twice weekly for 2 weeks every 3 weeks in patients with hematologic malignancies. Contact: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 13935. Phase I/II Trial of Subcutaneous Decitabine. Optimizing Genomic Methylation in patients with Intermediate-2 to high risk Myelodysplastic Syndromes (MDS). Pending. Contact: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 13937. A Pharmacokinetic and Pharmacodynamic Study of Oral CC-5013 in Subjects with Low or Intermediate-1 Risk Myelodysplastic Syndromes. Open. Contact: Stacy Moss. Phone: 813-745-8391.

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: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 14154. SCIOS-A randomized, multicenter, open-label, modified dose ascension. Parallel study of the safety, tolerability, and efficacy of oral SCIO-469 in low to intermediate-1 risk patients with MDS. Contact: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 13346. A randomized, placebo-controlled, double-blind trial of the administration of the MDR Modulator, Zosuquidar Trihydrochloride, during conventional induction and post-remission therapy in patients >60 years with newly diagnosed AML, Refractory Anemia with Excess Blasts in Transformation, or High-Risk Refractory Anemia with Excess Blasts. Contact: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. BMT CTN 0201. A Phase III Randomized, Multicenter Trial Comparing G-CSF Mobilized Peripheral Blood Stem Cell with Marrow Transplantation from HLA Compatible Unrelated Donors. This is a phase III trial using comparing G-CSF mobilized peripheral blood stem cell with marrow transplantation from HLA compatible unrelated donors to treat myelodysplastic syndromes. Eligible patients must be between the ages of 0–66, have acute leukemia, myelodysplasia, chronic myeloid leukemia, or other myeloproliferative disease, adequate organ function, a 6/6 or 5/6 HLA-A, B, and DRB1 matched unrelated donor, and able to give signed informed consent prior to enrollment. This is a multi-center study. Contact: Stacy Moss. Phone: 813-745-8391.

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,



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 institutional subscription rate of \$2,373), and the worldwide Centers of Excellence patient referral service.

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

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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

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. J0051. Dose finding study of Bryostat-1 and GM-CSF in Refractory Myeloid Malignancies. Contact: Lisa Malick. Phone: 410-502-0735.

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. 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), Chronic Myelomonocytic Leukemia, and Acute Myeloid Leukemia (AML). Contact: Tianna Dausen. Phone: 410-502-7110.

Johns Hopkins Oncology Center, Baltimore, MD. J0254. Phase I study of Flavopiridol in timed sequential combination with Cytosine Arbinoside and Mitoxantrone for adults with poor-risk acute leukemias and myelodysplasias. Contact: Jackie Greer. Phone: 410-614-1329.

Johns Hopkins Oncology Center, Baltimore, MD. J0466. Phase I and Pharmacological Trial of 17-Allylamino-17 Demethoxygeldanamycin (17-AAG) and Cytarabine in Refractory Leukemia and Myelodysplastic Syndromes. Contact: Caryn Salito. Phone: 410-502-7114.

Johns Hopkins Oncology Center, Baltimore, MD. J0330. Phase I study of Flavopiridol in combination with Imatinib Mesylate in Bcr/Abl+ hematological malignancies. Contact: Tianna Dausen. Phone: 410-502-7110.

Johns Hopkins Oncology Center, Baltimore, MD. J0434. Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Contact: Jackie Greer. Phone: 410-614-1329.

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 II study of combination of Thymoglobulin and cyclosporine in patients with newly diagnosed aplastic anemia or with hypoplastic myelodysplastic syndromes. The purpose of this study is to determine the efficacy of the combination of thymoglobulin, methylprednisone, cyclosporine and G-CSF in achieving response and to assess the effect of treatment on transfusion requirements and overall survival. Eligible patients must have a diagnosis of severe aplastic

anemia or MDS with bone marrow cellularity less than 30%, two of three peripheral counts low with ANC less than 500/mL, Plt less than 20,000/mL or reticulocyte count less than 40,000/mL. Patients with MDS who have received prior biological therapy (not chemotherapy), age 15 or greater, adequate renal and hepatic function, no other investigational therapy in the past 14 days, able to comply with the need for contraception during the entire study period. Exclusion criteria include active and uncontrolled pulmonary, cardiac, neurological or other medical illness that would interfere with study treatment, pregnant or breast-feeding, HIV positive or active and uncontrolled infection. Contact: Farhad Ravandi, MD. Phone: 713-745-0394.

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 Syndromes (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 Syndromes (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 Syndromes. 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 Syndromes. 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 Syndromes (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 Syndromes. 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 Syndromes, 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 Syndromes, Polycythemia Vera, Atypical CML or CMML with PDGF-R Fusion Genes, or Mastocytosis with Gleevec (ST1571). 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 patients ≥ 50 yrs with newly diagnosed and previously

untreated acute myeloid leukemia (AML) and high-risk myelodysplastic syndromes (MDS) ($\geq 10\%$ 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 > 1 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.

Mayo Clinic, Phoenix, AZ. PO2978. Study of Lonafarnib versus placebo in treatment of subjects with myelodysplastic syndromes or chronic myelomonocytic leukemia who are platelet transfusion-dependent with or without anemia. Contact: James Slack, MD. Phone: 480-342-2088.

Mayo Clinic, Phoenix, AZ. C1CL670AUS03. Phase II study of Exjade (deferasirox) for treatment of transfusional iron overload in low-risk and intermediate-1 transfusion-dependent MDS patients using ferritin monitoring. Contact: James Slack, MD. Phone: 480-342-2088.

Mayo Clinic, Rochester, MN. DACO-020. A Phase II study of decitabine administered daily for 5 days every 4 weeks to adults with advanced stage myelodysplastic syndromes. Contact: David P. Steensma, MD. Phone: 507-538-0107.

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. 05-H-0201. Metoclopramide to Treat Anemia in Patients with Myelodysplastic Syndromes (MDS). The study drug, metoclopramide, may help increase blood red blood cell counts, reduce anemia symptoms, and/or reduce dependence on transfusions. If eligible to participate, consenting subjects will take metoclopramide by mouth 3 times a day for 20 weeks. Subjects will be followed for safety and effectiveness monitoring at either the NIH or through their home physician. If you have been diagnosed with MDS and are age 18 to 72, you may be able to participate in this clinical trial. Contact: Carol Webb, MSRN. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 01-H-0162. Stem Cell Transplantation for Older Patients with Myelodysplastic Syndromes. 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, RN. Phone: 301-402-3595.

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, RN. Phone: 301-402-3595.

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

years of age and have been diagnosed with advanced myelodysplastic syndromes, 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 Musse, MSRN. Phone: 301-496-3841.

National Heart, Lung, and Blood Institute, Bethesda, MD. 05-H-0206. A Pilot Study of Alemtuzumab (Campath®) in Patients with Myelodysplastic Syndromes (MDS). The study drug, a monoclonal antibody, may help increase blood counts, reduce anemia symptoms, and/or reduce dependence on transfusions. If eligible to participate, consenting subjects will receive an intravenous infusion of study medication alemtuzumab (Campath®) once a day for 10 days. Subjects will be admitted to the NIH Clinical Center hospital for study drug initiation. If the study drug infusion is tolerated well, the subject may be discharged and receive the remainder of the treatment course as an outpatient. Contact: Carol Webb, MSRN. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 99-H-0050. Non-Myeloablative Allogeneic Peripheral Blood Mobilized Hematopoietic Precursor Cell Transplantation for Hematologic Malignancies in High Risk Patients and in Patients With Debilitating Hematologic Diseases. If you have been diagnosed with MDS, you may be able to participate in a stem cell transplant clinical trial designed to evaluate methods to decrease graft versus host disease, promote engraftment, and improve immune system recovery following a bone marrow stem cell transplant procedure.

You must have an HLA-matched family member to participate. You will be given chemotherapy followed by a transfusion of stem cells and lymphocytes from your donor, which will replace your immune system with the immune system of your healthy donor. Post transplant therapy is designed to reduce the risk of graft versus host disease. We do the blood testing free of charge to see if your family member is a match. We pay for all medical costs related to the transplant procedure. You must be available to live near NIH for approximately 3 months. We also provide a daily allowance to help with living expenses while you are on the study and living away from home. Contact: Rose Goodwin. Phone: 301-594-8013.

New York Medical College/Westchester Medical Center, Valhalla, NY. Pivotal randomized study of Lonafarnib Versus Placebo in the treatment of subjects with MDS or CMML who are platelet transfusion dependent with or without anemia. Contact: Dr. Karen Seiter. Phone: 914-493-7514.

New York Medical College/Westchester Medical Center, Valhalla, NY. Log 6252. 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. I35904. A trial of Campath-1H (Alemtuzumab) for Myelodysplastic Syndromes. This is an open label trial of a single course of subcutaneous Campath-1H monotherapy to improve the cytopenias of MDS patients with a Low to Intermediate-2 IPSS score. The study is designed as a two-stage Phase II

trial with a total of 20 subjects and stopping rules for both safety and futility. Contact: Minoo Battiwalla, MD. Phone: 716-845-1145.

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.

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, R.N. 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. INFT2. Allogeneic stem cell and natural killer cell transplantation for children less than 2 years of age with hematologic malignancies. Contact: Wing Leung, 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. REFSC. 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'-deoxycytidine) versus supportive care in adults with advanced-stage myelodysplastic syndromes. 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 syndromes. 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 syndromes 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.

Thomas Jefferson University, Philadelphia, PA. A multicenter, single-arm, open-label study of the efficacy and safety of CC-5013 monotherapy in RBC transfusion-dependent subjects with Myelodysplastic Syndromes. Contact: Emmanuel C. Besa, MD. Phone: 215-955-0356.

Tufts-New England Medical Center, Boston, MA. Phase II study of reduced intensity allogeneic stem cell transplant for the treatment of myelodysplastic syndromes. This is a trial by the Eastern Cooperative Oncology Group using a reduced intensity preparative regimen pioneered here at Tufts-NEMC to cure patients with MDS and a genetically compatible related or unrelated donor. 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. 04154. Phase I/II trial of subcutaneous decitabine optimizing genomic methylation in patients with myelodysplastic syndromes. Contact: Daruka Mahedevan, MD. Phone: 520-626-0191.

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: 520-626-0191.

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 (Thalomid) 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. 11884A. High-dose cytarabine/mitoxantrone followed by autotransplantation for therapy-related MDS. Contact: Margaret Green, RN. Phone: 773-702-0267.

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.

Mayo Clinic, Phoenix, AZ. C1CL670AUS03. An open label, safety and tolerability study of deferasirox for treatment of transfusional iron overload in low-risk and intermediate-1 MDS patients using ferritin monitoring. Contact: Elizabeth Rich, MD. Phone: 773-702-0239.

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 Massachusetts Medical Center, Worcester, MA. Pilot Study to Test the Efficacy of the Anti-CD52 Antibody Campath-1H in Combination with the Growth Factor GM-CSF in Improving the Cytopenias of Patients with Myelodysplastic Syndromes. The purpose of this study is to evaluate the effects of Campath-1H and GM-CSF, in combination, on the low counts seen in MDS. What happens in MDS is a cell in your bone marrow becomes abnormal and starts to grow and multiply. However, the abnormal cells that this bone marrow cell makes die via cell suicide on the way to the blood, resulting in the low blood counts seen in MDS. We hope that Campath-1H will target these abnormal bone marrow cells and cause them to die, while GM-CSF will cause the normal cells to grow and multiply more. If true, these drugs would improve the low blood counts. Both of these drugs must be given by injection. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. A pilot study to test the efficacy of coenzyme Q10 in patients with low to intermediate-1 risk myelodysplastic syndromes. The purpose of this study is to test the efficacy of coenzyme Q10 in improving abnormalities seen in bone marrow cells of patients with MDS. One of the abnormalities that tend to occur in the bone marrow cells involves part of the cell called the mitochondria. The mitochondria are like energy producing factories in your cells. Coenzyme Q10 is used by the mitochondria to do their job. Coenzyme Q10 may potentially correct the abnormalities seen in the cells of the bone marrow in MDS. Coenzyme Q10 is a natural, non-toxic substance that can be taken by mouth. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. A pilot study to test the efficacy of curcumin and gingerol in patients with myelodysplastic syndromes. The purpose of this study is to test the efficacy of the natural compounds curcumin and gingerol in improving the low blood counts seen in patients with MDS. In MDS, a patient's bone marrow makes more cells than usual that eventually turn into blood cells. However, the increased number of blood cells made die by suicide on the way to the blood. A chemical substance called TNF- α causes the increased cell suicide. Curcumin and gingerol inhibit TNF- α . They are also non-toxic substances, making them ideal for the generally older patient population of MDS, especially since two thirds of the population will not go on to develop acute leukemia. These compounds can be taken at home by mouth. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. Oral iron chelation (ICL670) in patients with low to intermediate-1 risk myelodysplastic

syndromes. Some patients with MDS are dependent on transfusions to treat their low blood counts. When a patient receives a transfusion, they also get iron that is contained in the blood. This becomes a problem because the body cannot rid itself of iron and a buildup of iron can be toxic and even lethal for the patient. ICL670, also called deferasirox, can get rid of some of this extra iron accumulating in the blood and can thus reduce the morbidity associated with frequent transfusions sometimes required for MDS. Deferasirox can be taken by mouth. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. A Pivotal Randomized Study of Lonafarnib versus Placebo in the Treatment of Subjects with Myelodysplastic Syndromes or Chronic Myelomonocytic Leukemia who are Platelet Transfusion Dependent with or without Anemia. This study is attempting to test the efficacy of Lonafarnib against the abnormal cells found in the bone marrow of patients with MDS. Lonafarnib inhibits a certain protein in your cells that causes the cell to grow and multiply. We believe that Lonafarnib will stop the abnormal cells in the bone marrow from multiplying so that more normal cells can get to the blood. Lonafarnib can be taken by mouth. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. A Phase II Trial of Combination Therapy with Thalidomide, Arsenic Trioxide, Dexamethasone, and Ascorbic Acid (TADA) in Patients with Chronic Idiopathic Myelofibrosis or Overlap Myelodysplastic/Myeloproliferative Disorders. The purpose of this study is to see if Thalidomide in combination with arsenic trioxide can improve the low blood counts seen in MDS. In MDS, the cells in the bone marrow are increased, but the blood cells die in greater numbers via cell suicide, resulting in the low blood counts. Thalidomide works to decrease this cell suicide and raise blood counts, while arsenic trioxide works to cause cell suicide of some of the abnormal cells in the bone marrow. We believe the result will be more normal blood cells getting to the blood. The Dexamethasone and ascorbic acid are used to improve the function of the Thalidomide and arsenic trioxide. Thalidomide can be taken by mouth, but arsenic must be administered through an IV. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. Phase 1-2a Study of TLK199HCl Liposomes for Injection in Myelodysplastic Syndromes. The purpose of this study is to test the efficacy of TLK in improving the low blood counts seen in MDS. One of the main causes of death seen from MDS is infection. This occurs because the white blood cells that fight infections are lowered in number due to the disease. TLK increases the white blood cell count, making it easier for a patient's body to fight infection and thus lowering their chance of dying from infection. This drug is administered through an IV, so patients must come into the hospital to receive this treatment. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. A pilot study to determine efficacy of combining Vidaza and arsenic trioxide for the treatment of patients with intermediate and high risk myelodysplastic syndromes. The purpose of this study is to determine the efficacy of Vidaza and arsenic trioxide, in combination, at improving the low blood counts seen in MDS. As stated in a description above, Vidaza prevents the silencing of good genes in your cell that prevent the cell from growing out of control. This means that Vidaza will hopefully prevent abnormal cells from growing out of control. Arsenic, as described above, works in a different way to do the same thing. Arsenic prevents abnormal cells from growing by causing them to commit suicide. It is hoped that in combination these drugs will increase the blood counts in patients with MDS. Arsenic trioxide must be given via an IV, while Vidaza must be given through an injection. Contact: Azra Raza, MD. Phone: 508-856-3561.

University of Massachusetts Medical Center, Worcester, MA. A Pilot Study to Determine the Efficacy of Combining Vidaza and Thalidomide for the Treatment of Myelodysplastic Syndromes and Acute Myeloid Leukemia. This study is assessing the efficacy of Vidaza and Thalidomide, in combination. We hope that these drugs will increase the low blood counts seen in patients with MDS. There are certain genes in your cell that keep it from growing out of control. These genes get what we call 'silenced' in MDS and the now abnormal cell grows out of control. However, the cells that it makes die via cell suicide before they reach the blood, resulting in the low blood count. Vidaza prevents the silencing of the good genes so that the cell does not grow out of control and die on the way to the blood. Thalidomide works to decrease the cell suicide of normal cells and raise blood counts. In combination, we hope that these drugs will raise the blood counts in MDS. Thalidomide can be taken by mouth, while Vidaza must be given via an injection. Contact: Azra Raza, MD. Phone: 508-856-3561.

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 syndromes. 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 Juckett, 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 Syndromes: 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.

Wake Forest University School of Medicine, Winston-Salem, NC. CCCWFU-29304. Phase II Study of Arsenic Trioxide and Dose-Escalated Cholecalciferol in Myelodysplastic Syndromes: The purpose of this study is to determine how many patients with myelodysplastic syndromes (MDS) respond to the combination treatment with arsenic trioxide and cholecalciferol (vitamin D₃). All MDS patients are eligible if they have a life expectancy of at least six months. Arsenic trioxide is administered daily for 5 days intravenously (as a "loading" dose) followed by twice a week administration. Vitamin D₃ is given at 100 microgram/day by mouth and the dose is increased by 50 microgram/d every three months up to a year in patients who have no toxicity and did not achieve complete remission. Bone marrow samples are obtained before and during treatment to look at response with morphological and biological parameters. Patients may remain on the study for up to one year. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

Washington University School of Medicine, St. Louis, MO. 03-1277. A phase III randomized, multicenter trial comparing G-CSF mobilized peripheral blood stem cell with marrow transplantation from HLA compatible unrelated donors. Contact: Nick Fisher. Phone: 314-454-5090.

Washington University School of Medicine, St. Louis, MO. 01-1014. Tissue acquisition for analysis of genetic progression factors in hematologic diseases for AML and MDS. Contact: Nick Fisher. Phone: 314-454-5090.

Washington University School of Medicine, St. Louis, MO. 03-0187. CALGB 100002: Non-myeloablative allogeneic hematopoietic cell transplantation for patients with disease relapse or myelodysplasia after prior autologous transplantation. Contact: Nick Fisher. Phone: 314-454-5090.

Washington University School of Medicine, St. Louis, MO. 03-0349. A pilot study evaluating the safety and efficacy of AMD3100 for the mobilization and transplantation of HLA-matched sibling donor hematopoietic stem cells in patients with advanced hematologic malignancies. Contact: Nick Fisher. Phone: 314-454-5090.

Washington University School of Medicine, St. Louis, MO. 05-0141. A Phase I pharmacokinetic trial of decitabine administered as a 3-hour infusion to patients with acute myelogenous leukemia or myelodysplastic syndromes. Contact: Nick Fisher. Phone: 314-454-5090.

Washington University School of Medicine, St. Louis, MO. 04-0337. CALGB10105: A Phase II study of an oral VegF receptor tyrosine kinase inhibitor (PTK78/ZK222584) in myelodysplastic syndromes (MDS). Contact: Nick Fisher. Phone: 314-454-5090.

Western Pennsylvania Cancer Institute, Pittsburgh, PA. WPCI2004-17. Arsenic trioxide, ascorbic acid, filgrastim and erythropoietin for the treatment of myelodysplastic syndromes. Contact: Richard K. Shadduck, MD. Phone: 412-578-1034.

Western Pennsylvania Cancer Institute, Pittsburgh, PA. WPCI2004-37/AZA PH US 2004 CL003. A multicenter, randomized, open-label study comparing three alternative dosing regimens of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Richard K. Shadduck, MD. Phone: 412-578-1034.

Western Pennsylvania Cancer Institute, Pittsburgh, PA. WPCI2004-08/CALGB 10105. A Phase II study of an oral VegF receptor tyrosine kinase inhibitor (PTK787/ZK222584) in the treatment of myelodysplastic syndromes. Contact: Richard K. Shadduck, MD. Phone: 412-578-1034.

European Trials

AUSTRALIA

Peter MacCallum Cancer Centre, 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: John F. Seymour, MD. Phone: +613 9656 1697.

The Newcastle Mater Misericordiae 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, Brussels. 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. Ferrant. Phone: 32 2 764 1810 (1880).

ENGLAND

Kings College Hospital/Guys-Kings-Thomas School of Medicine. AZA PH GL 2003 CL 001. A randomized trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of myelodysplastic syndromes. Contact: Professor Ghulam J. Mufti. Phone: 00 44 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Randomized controlled trial of prolonged treatment with darbepoetin alpha and recombinant human granulocyte colony stimulating factor (GCSF) versus best supportive care in patients with low-risk MDS. Contact: Professor Ghulam J. Mufti. Phone: 00 44 207-346-3080.

The Royal Bournemouth Hospital. Multi-centre study of the role of 5-Azacitidine 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. CC5013-MDS-004. A phase III trial, three arms, randomized multi-center in double blind to evaluate the efficacy and toxicity of two doses of Lenalidomide versus placebo in subjects with IPSS low or Intermediate-1 risk MDS associated with deletion 5q and red blood cell transfusion-dependent anemia defined as having received >4 transfusions within 56 days of randomization of symptomatic anemia. Contact: Pierre Fenaux, MD. Phone: +33 1 48 95 70 50/70 51 pierre.fenaux@avc.ap-hp.fr.

Groupe Français des Myelodysplasies. THAL-MDS-200. A phase II multi-center study of Thalidomide at low dose for the treatment of patients with IPSS low or Intermediate-1 risk MDS. Contact: Didier Bouscary, MD. Phone: +33 1 40 51 65 43 bouscary@cochin.inserm.fr.

Groupe Français des Myelodysplasies. ICL670. A multi-center study to evaluate the efficacy and tolerance of treatment by ICL670 (20 mg/kg/d) during 1 year in RBC transfusion-dependent subjects with hemosiderosis. Contact: Christian Rose. Phone: +33 3 20 87 45 32 rose.christian@ghicl.net.

Groupe Français des Myelodysplasies. MAQ2005. A phase II study of intensive chemotherapy combined to quinine in high risk MDS with PGP expression. Contact: Pierre Fenaux, MD. Phone: +33 1 48 95 70 50/70 51 pierre.fenaux@avc.ap-hp.fr. or Stephane de Botton s.debotton@voila.fr.

Groupe Français des Myelodysplasies. 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: Pierre Fenaux, MD. Phone: +33 1 48 95 70 50/70 51 pierre.fenaux@avc.ap-hp.fr.

Groupe Français des Myelodysplasies. GFMaza05. Phase II study on maintenance treatment with azacitidine in high risk MDS patients in response after intensive chemotherapy. Contact: Claude Gardin, MD. Phone: +33 1 48 95 70 50/70 51 claude.gardin@avc.aphp.fr.

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 veyn@marseille.fnclcc.fr.

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. Allo/Treo-Flud/MDSsAML. 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: +49-40-42803-5864.

University Hospital Hamburg. RICMAC-MDSsAML. EBMT: Dose-reduced versus standard conditioning followed by allogeneic stem cell transplantation in patients with MDS or sAML. A randomized phase III study. Contact: Nicolaus Kröger, MD. Phone: +49-40-42803-5864.

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. EVTAC trial. Tacrolimus and everolimus as graft-versus-host disease prophylaxis for patients with MDS or AML receiving hematopoietic stem cells from HLA-compatible siblings or unrelated donors. Contact: Uwe Platzbecker, MD. Phone: +49-351-458-4190.

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: +49-351-458-4190.

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: +49-351-458-4190.

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 ceruloplasmin level, analysis of transferring receptor mutation and also TNF-alpha promoter gene polymorphism in MDS patients. Contact: Judit Varkonyi, MD, PhD. Phone/Fax: 361-355-8251.

ISRAEL

Tel-Aviv Sourasky Medical Center. OCC5013-MDS-004. Randomized 3-arm controlled trial: 2 doses of Revlimid vs control for transfusion-dependent 5q- MDS patients. Contact: Dr. Moshe Mittelman. Phone: +972 (0) 3-697-3366.

ITALY

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. MDS-05-1. A pilot study with high dose darbepoetin in transfusion-dependent, low-intermediate risk 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. MDS-05-2. A pilot study with high dose darbepoetin plus peg-filgrastim in transfusion-dependent, low-intermediate risk 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. PO2978. A randomized trial with Lonafarnib (Sarasar) vs

placebo in myelodysplastic syndromes or chronic myelomonocytic leukemias who are platelet transfusion dependent. 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 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 randomized trial with 5-azacitidine plus best supportive care versus conventional care treatments in high-risk 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 darbepoietin-alpha in low-risk, anemic 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 Gasthuisberg, 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. Verhoef. 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 2x2 randomized multicenter 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.

VU University Medical Center, Amsterdam. Impact on apoptosis of immature myeloid and erythroid progenitor cells and its relation to immune escape mechanisms of a standardized regimen of epoëtime bêta (NeoRecormon®) and granulocyte colony-stimulating-factor (Neupogen®) in low-risk myelodysplasia. Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hematologie.nl).

VU University Medical Center, Amsterdam. Randomized phase II trial with infliximab (Remicade) in patients with myelodysplastic syndrome and a relatively low risk of developing acute leukemia (EORTC 06023). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.eortc.be).

VU University Medical Center, Amsterdam. Antithymocyte globulin (ATG) and cyclosporine (CsA) to treat patients with MDS. A randomized trial comparing ATG and CsA with best supportive care (HOVON60). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hovon.nl).

VU University Medical Center, Amsterdam. Randomized induction and post induction therapy in adult patients (d 60 yrs of age) with acute myelocytic leukemia (AML) or refractory anemia with excess of blasts (RAEB, RAEB-t) with IPSS score e1.5 (HOVON 42). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hovon.nl).

VU University Medical Center, Amsterdam. Randomized induction and post induction therapy in older patients (e 61 yrs of age) with acute myelocytic leukemia (AML) and refractory anemia with excess of blasts (RAEB, RAEB-t) with IPSS score e 1.5 (HOVON43). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hovon.nl).

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. 2001395. 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: Maria Consuelo del Cañizo, MD. Phone: +34 923 291384.

Hospital Universitario del Salamanca, Salamanca. 200500045473. Chelation therapy in RBC transfusion-dependent myelodysplastic syndromes (MDS) patients. Contact: Maria Consuelo del Cañizo, MD. Phone: +34 923 291384.

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.

New MDS Publications

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

Kufner S, Fleischer RP, Kroell T, et al. Serum-free generation and quantification of functionally active Leukemia-derived DC is possible from malignant blasts in acute myeloid leukemia and myelodysplastic syndromes. *Cancer Immunol Immunother.* 2005 Oct;54(10):953–70.

Gurkan E, Tanriverdi K, Baslamisli F. Telomerase activity in myelodysplastic syndromes. *Leuk Res.* 2005 Oct;29(10):1131–1139.

Cazzola M, Malcovati L, Della Porta MG, Pascutto C, et al. Prognostic Factors and Life Expectancy in Myelodysplastic Syndromes Classified According to WHO Criteria: A Basis for Clinical Decision Making. *J Clin Oncol.* 2005 Sep 26.

Stasi R, Abruzzese E, Lanzetta G, et al. Darbepoetin alfa for the treatment of anemic patients with low- and intermediate-1-risk myelodysplastic syndromes. *Ann Oncol.* 2005 Sep 15.

- Strom SS, Gu Y, Gruschkus SK, et al.** Risk factors of myelodysplastic syndromes: a case-control study. *Leukemia*. 2005 Sep 15.
- Klein CE, Kastrissios H, Miller AA, et al.** Pharmacokinetics, pharmacodynamics and adherence to oral topotecan in myelodysplastic syndromes: a Cancer and Leukemia Group B study. *Cancer Chemother Pharmacol*. 2005 Sep 13:1–8.
- Zwierzina H, Suci S, Loeffler-Ragg J, et al.** Low-dose cytosine arabinoside (LD-AraC) vs LD-AraC plus granulocyte/macrophage colony stimulating factor vs LD-AraC plus Interleukin-3 for myelodysplastic syndrome patients with a high risk of developing acute leukemia: final results of a randomized phase III study (06903) of the EORTC Leukemia Cooperative Group. *Leukemia*. 2005 Sep 8.
- Giagounidis AA, Germing U, Strupp C, et al.** Prognosis of patients with del(5q) MDS and complex karyotype and the possible role of lenalidomide in this patient subgroup. *Ann Hematol*. 2005 Sep;84(9):569–71.
- Tehranchi R, Fadeel B, Schmidt-Mende, et al.** Antiapoptotic role of growth factors in the myelodysplastic syndromes: concordance between in vitro and in vivo observations. *Clin Cancer Res*. 2005 Sep 1;11(17):6291–9.
- Lindberg EH.** Strategies for biology- and molecular-based treatment of myelodysplastic syndromes. *Curr Drug Targets*. 2005 Sep;6(6):713–25.
- Papageorgiou SG, Pappa V, Papageorgiou E, et al.** Absence of p16 and p27 gene rearrangements and mutations in de novo myelodysplastic syndromes. *Eur J Haematol*. 2005 Sep;75(3):193–8.
- Sole F, Luno E, Sanzo C, Espinet B, Sanz GF, et al.** Identification of novel cytogenetic markers with prognostic significance in a series of 968 patients with primary myelodysplastic syndromes. *Haematologica*. 2005 Sep;90(9):1168–78.
- Germing U, Kuendgen A.** Perspectives in the prognostication of myelodysplastic syndromes. *Haematologica*. 2005 Sep;90(9):1157–9.
- Malcovati L.** Refining the prognostic value of cytogenetic abnormalities in myelodysplastic syndromes. *Haematologica*. 2005 Sep;90(9):1153B.
- Bennett JM, Komrokji RS.** The myelodysplastic syndromes: Diagnosis, molecular biology and risk assessment. *Hematology*. 2005 Sep–Oct;10 Suppl 1:258–69.
- Cortelezzi A, Fracchiolla NS, Mazzeo LM, et al.** Endothelial precursors and mature endothelial cells are increased in the peripheral blood of myelodysplastic syndromes. *Leuk Lymphoma*. 2005 Sep;46(9):1345–51.
- Ogata K, Yoshida Y.** Clinical implications of blast immunophenotypes in myelodysplastic syndromes. *Leuk Lymphoma*. 2005 Sep;46(9):1269–74.
- Abe S, Yamamoto K, Hasegawa M, et al.** Bone marrow cells of myelodysplastic syndromes exhibit significant expression of apollon, livin and ILP-2 with reduction after transformation to overt leukemia. *Leuk Res*. 2005 Sep;29(9):1095–6.
- Auberger J, Dlaska M, Auberger T, et al.** Increased CD133 expression in bone marrow of myelodysplastic syndromes. *Leuk Res*. 2005 Sep;29(9):995–1001.
- Steidl C, Steffens R, Gassmann W, et al.** Adequate cytogenetic examination in myelodysplastic syndromes: analysis of 529 patients. *Leuk Res*. 2005 Sep;29(9):987–93.
- Gyan E, Frew M, Bowen D, et al.** Mutation in RAP1 is a rare event in myelodysplastic syndromes. *Leukemia*. 2005 Sep;19(9):1678–80.
- Amin HM, Yang Y, Shen Y, Estey EH, et al.** Having a higher blast percentage in circulation than bone marrow: clinical implications in myelodysplastic syndrome and acute lymphoid and myeloid leukemias. *Leukemia*. 2005 Sep;19(9):1567–72.
- Marcucci G, Mrozek K, Ruppert AS, et al.** Prognostic factors and outcome of core binding factor acute myeloid leukemia patients with t(8;21) differ from those of patients with inv(16): a Cancer and Leukemia Group B study. *J Clin Oncol*. 2005 Aug 20;23(24):5705–17.
- Schmid C, Schleuning M, Ledderose G, Tischer J, Kolb HJ.** Sequential regimen of chemotherapy, reduced-intensity conditioning for allogeneic stem-cell transplantation, and prophylactic donor lymphocyte transfusion in high-risk acute myeloid leukemia and myelodysplastic syndrome. *J Clin Oncol*. 2005 Aug 20;23(24):5675–87.
- van Besien K, Artz A, Smith S, et al.** Fludarabine, melphalan, and alemtuzumab conditioning in adults with standard-risk advanced acute myeloid leukemia and myelodysplastic syndrome. *J Clin Oncol*. 2005 Aug 20;23(24):5728–38.

Kerbaux DM, Lesnikov V, Abbasi N, Seal S, Scott B, Deeg HJ. NF- κ B and FLIP in arsenic trioxide (ATO)-induced apoptosis in myelodysplastic syndromes (MDS). *Blood*. 2005 Aug 16.

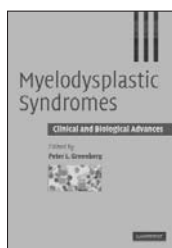
Steensma DP, Dewald GW, Lasho TL, et al. The JAK2 V617F activating tyrosine kinase mutation is an infrequent event in both "atypical" myeloproliferative disorders and myelodysplastic syndromes. *Blood*. 2005 Aug 15;106(4):1207–9.

Bennett JM. The clinical implications of the World Health Organization's classification of myelodysplastic syndromes. *Current Hematology Reports*. 2005 May;4(3):175–81.

Feldman EJ. Farnesyltransferase inhibitors in myelodysplastic syndromes. *Current Hematology Reports*. 2005 May;4(3):186–90.

Jadersten M, Montgomery SM, Dybedal I, Porwit-Macdonald A, Hellstrom-Lindberg E. Long-term outcome of treatment of anemia in MDS with erythropoietin and G-CSF. *Blood*. 2005 Apr 19.

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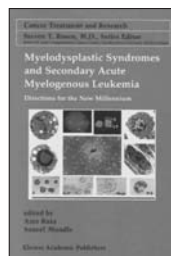


Myelodysplastic Syndromes: Clinical and Biological Advances

Peter L. Greenberg, MD
Stanford University
School of Medicine, California

Hardback, Nov. 2005/320pp., illus., ISBN: 0521496683/\$120.00
Cambridge press

A comprehensive reference on all aspects of the clinical classification underlying pathogenetic mechanisms and treatment of the myelodysplastic syndromes, *Myelodysplastic Syndromes* stands out as a definitive text on the genetics, pathophysiology, and clinical management from of this wide range of syndromes. Authored by international experts, this book provides a state-of-the-art update of the current status and recent advances in the field. This book will be a valuable resource to clinicians and researchers who wish to learn more about myelodysplastic syndromes.

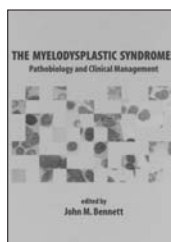


Myelodysplastic Syndromes & Secondary Acute Myelogenous Leukemia: Directions for the New Millennium (Cancer Treatment and Research)

Edited by:
Azra Raza, MD and
Suneel D. Mundle, Ph.D.

June 2001/278pp., illus., ISBN: 0792373660/\$198.00
Springer Science + Business Media, Inc.

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



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

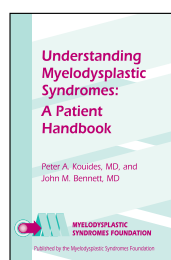
This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse

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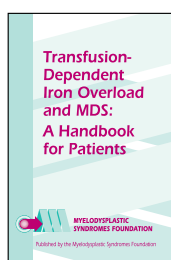
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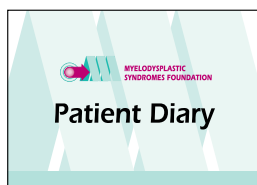
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A.



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Peter A. Kouides, MD; John M. Bennett, MD

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D. **Your Journal: Learning About Myelodysplastic Syndromes (MDS)**

Supported by a grant from Celgene Corporation.



E. **PBS Program Videotape Healthy Body, Healthy Mind: Learning About Myelodysplastic Syndromes**

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

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

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

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



Innovating for life

Telik has provided the MDS Foundation with an educational grant to support the Foundation's work.

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In 2002, Angel Flight 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, Angel Flight pilots also offer free flights for other humanitarian reasons. Each summer, Angel Flight'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, Angel Flight 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.

Angel Flight 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. Angel Flight is the oldest and largest national volunteer pilot organization in the United States. For more information about Angel Flight, visit www.angelflight.org or call toll-free (888) 4-AN-ANGEL (888-426-2643).

CONTACT AF:

Mailing Address

Angel Flight
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info@angelflight.org

Phone:

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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:

Angel Flight 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 Angel Flight goes directly to program services.

Volunteer Opportunities:

Angel Flight is currently seeking volunteer pilots in many areas of the country. For more information, visit www.angelflight.org or call (888) 4-AN-ANGEL.



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Somewhat, depending on type and size of aircraft.

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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 eight international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, France, and Japan. The Ninth International Symposium is being held in May 2007 in Florence, Italy.

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>



Pfizer has provided the MDS Foundation with an educational grant to support the Foundation's work.

Blood & Marrow Transplant Newsletter

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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.

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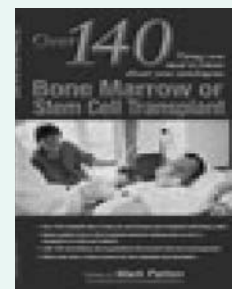
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Mrs. Mary Ann Opanowicz

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

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Richard and Sally Jones
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Mrs. Mary Ann Opanowicz (continued)

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

Charles Jager
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Winnie and Steve Jager
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A memorial fund has been established in the name of

Mr. Kenneth Platt

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Schering-Plough has provided the MDS Foundation with an educational grant to support the Foundation's work.

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A memorial fund has been established in the name of

Mr. Joe Royal

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Awilda M. Durham, *Woodbridge, VA*

A memorial fund has been established in the name of

Mr. Leonard Sherman

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Mr. Maury Simpson

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Suzanne Fleischman Memorial Fund for Patient Advocacy

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

New donations have been made by:

Edward Fleischman, Prescott, AZ
Daniel and Sandra Linn, La Jolla, CA

Patient Referrals

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

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

Please contact us at:

1-800-MDS-0839 (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>.

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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 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.



Novartis Oncology has provided the MDS Foundation with an educational grant to support the Foundation's work.