THE CHALLENGE OF MYELODYSPLASIA

The myelodysplastic syndromes (MDS) are a heterogeneous group of disorders ranging the gamut from patients with moderate anemia with normal neutrophil and platelet counts to others with essentially frank leukemia. Clinical courses can range from a few months to many years and it is clear that a number of biologically distinct disorders are combined under this rubric, awaiting further molecular characterization to allow better classification. MDS may be the most common hematopoietic neoplasm in adults and appears to be rising in incidence, in part because of the aging of the population in the Western world. It is probably underdiagnosed and may be the cause of some of the mild to moderate anemia encountered in older people which is attributed to “chronic disease.” Because of the availability of some new approaches to treatments, there has been increased interest in the problems posed by MDS on the part of clinicians, laboratory scientists and funding agencies. Pharmaceutical companies and the horde of investment analysts who trail one step behind have also recognized that there is a considerable potential market for an effective treatment given to lots of patients over a long period of time. On a positive note, this has resulted in an increase in the number of clinical trials. However, there has also been an increase in the amount of preliminary, sometimes incomplete information from a variety of sources, which is often confusing and potentially misleading for patients and physicians.

Unfortunately, there are very few randomized trials comparing active treatment with what was, until at least recently, the standard of supportive care. Most reports are difficult for patients and physicians to assess the true response rates or side effect profiles of particular therapies.

Contents

Be a Bone Marrow Donor 5
PBS Presents 5
MDS Foundation Golf Tournament 6
Blood & Marrow Transplant News 6
8th International Symposium on MDS 7
MDS Centers of Excellence 8
MDS Patient Registry 10
MDS Walk-A-Thon Held 10
About the Foundation 11
MDS Foundation 2005 Initiatives 11
International Clinical Trials: An Update 12
MDS Membership Information 17
Patient Quality-of-Life Forum 25
Patient Referrals 25
John Peter Murphy Research Fund 26
MDS Educational Resources 26
Patient Services 27
A Living Endowment 28
In Memorium 29
Gifts to the Foundation 32
MDS Board of Directors 32

(continued on page 2)
Some Things We Would Like to Know About the Biology of MDS

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

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

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

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

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

- Gene expression studies in MDS are in their infancy

Problems in Interpreting the Results of Clinical Trials

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

Treatment

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

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

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

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

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

The Treatment Decision

Whether to Treat

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

And With What?

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

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

and it is not clear whether reduced-intensity regimens which are being explored in older patients will be associated with even higher rates of relapse.

Summary

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

REFERENCES


Share Your Stories With The MDS Community

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

PBS Presents

A new series on PBS, Healthy Body, Healthy Mind, offers a segment devoted to MDS and the MDS Foundation. Please check your local listing for this special segment of this new series. The Foundation offers its special thanks for Celgene’s support of a new health and wellness TV series, Healthy Body, Healthy Mind.

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

Be a Bone Marrow Donor

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

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

Give the Gift of Life!

OTHER SITES OF INTEREST:

ASBMT™ American Society for Blood and Marrow Transplantation: www.asbmt.org
International Bone Marrow Transplant Registry: www.isbmt.org
National Marrow Donor Program™: www.marrow.org
Blood & Marrow Transplant Information Network: www.bmtinfonet.org

Thank You to Our Pharmaceutical Partners

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

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

AML-type induction therapy needs to be considered in suitable patients with increasing numbers of blasts and associated cytopenias despite the lower response rates and allogeneic stem cell transplantation is suitable in younger patients with higher IPSS scores and progressive disease.9 High relapse rates remain a problem after “full” allogeneic transplantation for MDS...
MDS Foundation Charity Golf Tournament

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

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

The MDS Foundation would like to express our gratitude for the generous support given by Celgene, Pharmion, Apotex, Cell Therapeutics and Telik. The Foundation is confident that the amounts raised through this tournament will further research efforts, with the hope of some day finding a cure for this disease.

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

Blood & Marrow Transplant Newsletter

Blood & Marrow Transplant Newsletter is published four times annually by BMT InfoNet.

To subscribe, contact:

BMT InfoNet
2900 Skokie Valley Road, Suite B
Highland Park, IL 60035
Tel: 847-433-3313, Fax: 847-433-4599
E-Mail: help@bmtnfonet.org
Web: www.bmtnfonet.org

8th International Symposium on Myelodysplastic Syndromes

May 12–15, 2005
Nagasaki, Japan

President of Local Organizing Committee: Masao Tomonaga, MD

SCIENTIFIC COMMITTEE

John M. Bennett, MD (USA)
Yataro Yoshida (Honorary President)
Ketsuke Toyama (Honorary Chair)
David T. Bowen
H. Joachim Deeg
Theo J.M. de Witte
Pierre Ferraux
Ulrich Germain
Peter Greenberg
Henrik Hasle
Eva Helister-Lindberg
Michele M. Le Beau

SCIENTIFIC TOPICS
- Etiology and epidemiology
- Classification and diagnosis
- Prognostic factors
- Genetic abnormalities
- Apoptosis
- Stem cell biology
- Immuno-suppressive therapy
- Chemotherapy
- Hematopoietic stem cell transplantation
- New Agents
- Methylation
- Iron chelation
- Other biological factors
- MDS in children
- Supportive care and quality of life

ORGANIZING COMMITTEE

Masami Bessho
Tomoimitsu Hotta
Akhisana Kanamaru
Seiji Kojima
Kazutaka Kuriyama
Kinsuku Mitani
Takashi Murate
Tatsutoshi Nakahata
Shinji Nakao
Tomoki Nace
Kazuma Ohyashki
Mitsuhito Omine
Takashi Uchiyama

IMPORTANT INFORMATION

Second announcement and call for papers: October 2004
Deadline for abstract submission: January 15, 2005
For further information please contact:
Symposium Secretariat
Masao Tomonaga, MD
Dept. of Hematology, Molecular Medicine Unit
Atomic Bomb Disease Institute
Nagasaki University School of Medicine
1-12-4 Sakamoto
Nagasaki, 852-8523, Japan
Tel: (81) 95 849-7111
Fax: (81) 95 849-7113
Email: mds8th@convention.co.jp
Symposium Website:
URL: http://www2.convention.co.jp/mds8th
Abstract and Registration Forms are available from the MDS website:
http://www.mds-foundation.org

PHARMION

Pharmion has provided the MDS Foundation with unrestricted educational grants to support the Foundation’s work.

Pfizer

Pfizer has provided the MDS Foundation with unrestricted educational grants to support the Foundation’s work.
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 (or equivalent) program
- Recognized morphologic expertise in MDS
- Available cytogenetics and/or molecular genetics
- Ongoing research, including Institutional Review
- Board-approved clinical trials

The following centers have qualified as MDS Centers of Excellence:

**UNITED STATES**
- 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
- Cedars-Sinai Medical Center
- UCLA School of Medicine
- Los Angeles, California
- H. Philip Kolett, MD
- City of Hope National Medical Center
- Duarte, California
- Stephen J. Williams, 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
- Charles A. Hahn, MD
- Fred Hutchinson Cancer Research Center
- Seattle, Washington
- Joachim Deeg, MD
- Indiana University
- Indiana University Medical Center
- Indianapolis, Indiana
- Lanny Crisp, MD
- Johns Hopkins Oncology Center
- Johns Hopkins Institutions
- Baltimore, Maryland
- Steven D. Golos, MD
- Mayo Clinic
- Rochester, Minnesota
- James L. Slack, MD
- Mayo Clinic
- Jacksonville, Florida
- Alvaro Mozos-Aspilia, MD
- Mayo Clinic
- Rochester, Minnesota
- Louis Leitendle, MD
- MCP Hahnemann University
- Philadelphia, Pennsylvania
- Emmanuelle C. Besa, MD
- Medical College of Wisconsin
- Bone Marrow Transplant Program
- Milwaukee, Wisconsin
- David H. Vosito, MD, PhD, FACP
- Memorial Sloan-Kettering Cancer Center
- New York, New York
- Stephen D. Nimer, MD
- National Heart, Lung, and Blood Institute
- Bethesda, MD
- Elaine Sisand, MD
- New York Medical College/ Westchester Medical Center
- Valhalla, NY
- Zalmen A. Arlin Cancer Center
- Karen Seiter, MD
- New York Presbyterian Hospital
- Columbia College of Physicians and Surgeons
- New York, New York
- Charles Heiderstock, 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
- Roswell Park Cancer Center
- Buffalo, New York
- Maria R. Bauer, 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 Halman, MD
- Stanford University
- Stanford University Medical Center
- Stanford, California
- Patrick L. Greenberg, MD
- St. Jude Children’s Research Hospital
- Memphis, Tennessee
- Gregory Halle, 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 Mahidolvi, 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
- Lorri Maness, MD
- University of New Mexico
- Health Sciences Center
- Albuquerque, New Mexico
- Robert Holmes, MD
- University of Pennsylvania
- University of Pennsylvania Cancer Center
- Philadelphia, Pennsylvania
- Selma Luger, MD
- University of Rochester
- Rochester University 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
- Elhu E. Haydy, MD
- University of Texas Southwestern Medical School
- Dallas, Texas
- Ami Verma, MD
- Wake Forest University School of Medicine
- Comprehensive Cancer Center
- Winston-Salem, North Carolina
- Istvan Molnar, MD
- Washington University School of Medicine
- Barnard Cancer Center
- St. Louis, Missouri
- Eric J. Feldman, MD
- The Western Pennsylvania Cancer Center
- Pittsburgh, Pennsylvania
- Richard K. Shadduck, MD
- William Beaumont Hospital Cancer Center
- Royal Oak, MI
- Johannes Jayasim, MD
- OUTSIDE THE UNITED STATES
- A.C. Camargo Hospital–Cancer Center
- São Paulo, Brazil
- Luis Fernandes Lopes, MD, PhD
- Academic Hospital, Free University Amsterdam
- Amsterdam, The Netherlands
- G.J. Ossenkoppele, MD, PhD
- Athens University
- Evangelismos Hospital
- Athens, Greece
- Theofanis Economopoulos, MD
- Casa Sollevi Della Sofrenza Hospital
- S. Giovanni Rotondo, Italy
- Fillinimo Musto, MD
- Fundeni Clinical Institute
- Bucharest, Romania
- Radu Gologan, MD, PhD
- Hannover Medical School
- Medizinische Hochschule Hannover
- Hannover, Germany
- Prof. Dr. Arnold Ganier
- Heinrich-Heine University Düsseldorf
- University Hospital of Düsseldorf, Germany
- Ulrich Gerhard, MD
- Hôpital Avicenne University Paris XIII
- Bobigny, France
- Pierre Fenaux, MD
- Hôpital Claude Huriez, CHU Lille
- Prof. Pierre Calbry, MD
- Hôpital Curie, CHU Lille
- Service des Maladies du Sang
- Lille, France
- Francoise Delaporte, MD
- Hôpital Cochin-University Paris V
- Paris, France
- Prof. Francois Dayyan, P.U.-PH
- Hôpital Saint Louis
- University Paris VI
- Paris, France
- Prof. Christine Chomienne
- Hospital de Santa Maria
- Lisbon, Portugal
- John F. Lacroix, MD
- Hospital Universitario de Salamanca
- Salamanca, Spain
- Prof. Jose F. Salazar, MD
- Hospital Universitario La Fe
- Valencia, Spain
- Miguel A. Sanz, MD
- Instituto de Hematología and Blood Transfusion
- Prague, Czech Republic
- Jaroslav Cermak, MD, PhD
- Jagiellonian University, Collegium Medicum
- Krakow, Poland
- Aleksander Skotnicki, MD, PhD
- Johann Wolfgang Goethe University
- Frankfurt Main, Germany
- Johannes Alt, MD
- Karolinska Institute
- Huddinge University Hospital
- Stockholm, Sweden
- Eva Hakansson-Lindberg, MD, PhD
- King Chulalongkorn Memorial Hospital
- Pathumwan, Bangkok, Thailand
- Tanin Ingamumtornchai, MD
- King’s College Hospital
- Guy’s Kings Thomas School of Medicine
- London, England
- Prof. Gurmukh J. Multani
- Kyoto University Hospital
- Kiyoto, Japan
- Takashi Ushiyama, MD
- Ludwig Maximilians Universität
- Munich, Germany
- Torsten Hielm-Bjerck, MD
- Nagasaki University Hospital
- School of Medicine
- Atomic Bomb Disease Institute
- Nagasaki, Japan
- Prof. Masao Tomozumi
- Nippon Medical School
- Tokyo, Japan
- Koosuk Ogata, MD, PhD
- Odense University Hospital
- The University of Southern Denmark
- Odense, Denmark
- Gitte Birk Kehlet, MD
- Patras University Hospital
- Patras, Greece
- Nicholas C. Zoubos, MD, PhD
- Peter MacCallum Cancer Institute
- University of Melbourne
- East Melbourne, Victoria, Australia
- John F. Seymour, MD
- Rigshospitalet
- National University Hospital
- Copenhagen, Denmark
- Lars Kjeldsen, MD
- Royal Bournemouth Hospital
- Bournemouth, United Kingdom
- Sally Killick, MD
- Salama Medical School Hospital
- Morongoh, Iruna, Japan
- Akira Matsuda, MD
- St. Johannes Hospital,
- Heinrich-Heine University
- Düsseldorf, Germany
- Carlo Au, MD, PhD
- Tel-Aviv Sourasky Medical Center
- Tel-Aviv, Israel
- Morshia Mittelman, MD
- Tokyo Medical College
- Tokyo, Japan
- Kazuma Oshayashi, MD
- Universidade Federal de Ceara
- Ceará, Brazil
- Fernando Barroso Duarte, MD
- Universitat Hamburg
- Hamburg, Germany
- Nicolaos Kioger, MD, PhD
- Universitätsklinikum Carl Gustav Carus
- Dresden, Germany
- Uwe Platzbecker, MD
- University of Arhus
- The University Hospital Arhus
- Arhus, Denmark
- Professor Johan Lennell Nielsen
- University of Athens, Laikon Hospital
- Athens, Greece
- Nikos Varitis
- University of Cape Town
- Groote Schuur Hospital
- Cape Town, Cape South Africa
- Nicholas Novitzky, MD, PhD
- University of Dundee Medical School
- Dundee Teaching Hospital
- Dundee, Scotland
- David T. Brown, MD
- University of Florence
- Azienda OSP Careggi
- Florence, Italy
- University of Freiburg Medical Center
- Freiburg, Germany
- Wolf-Karsten Holmahn, MD, PhD
- University Hospital Benjamin Franklin
- Berlin, Germany
- University Hospital of Innsbruck
- Innsbruck, Austria
- University of Niemegen
- University Hospital St. Radboud
- Nijmegen, The Netherlands
- Theo J. de Witte, MD, PhD
- University of Padova Medical School
- Padua, Italy
- Marco Cazolli, MD
- University of Tasmania
- Royal Hobart Hospital
- Hobart, Tasmania, Australia
- Prof. Raymond L. Mountford, MD, FRCP, FRACP
- University of Toronto Hospital for Sick Children
- Toronto, Ontario, Canada
- Yipin Dong, MD
- University Tor Vergata
- Ospedale S. Eugenio
- Roma, Italy
- Sergio Amadri, MD
- University of Vienna
- Vienna, Austria
- Peter Valenti, MD
MDS Walk-A-Thon Held
Special Thanks to the Ingle Family

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

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

Donations on behalf of Lois Ingle were submitted by:
Beth Ingle, Rockford, IL
Richard and Lois Ingle, Battle Creek, MI
Michael and Julie Ingle, Battle Creek, MI
Don and Sandra Ingle, Lake Wales, FL
Dan and Rhonda Madden, Battle Creek, MI
Michelle Wooden, Delton, MI
R.J. and Michel Mullenix, Battle Creek, MI
Lawrence and Reva Zeno, Battle Creek, MI
Peg Case, Battle Creek, MI
Monica Thacker-Duncan, Battle Creek, MI
Marjorie Kiesling, Marshall, MI
Bernice Peck, Battle Creek, MI
Kathy Whitesell, Battle Creek, MI
Robert and Janet Damon, Battle Creek, MI
Durrel and Deanne Stults, Battle Creek, MI
Keith and Julie Sutton, Battle Creek, MI
Robert and Margaret Cunningham, Battle Creek, MI
Maxine Phillips, Battle Creek, MI
Jerome and Kari Crane, Pecatonica, IL
Doni and Jan Bain, Battle Creek, MI
Judy Stone, Battle Creek, MI
Pauline Bicksford, Battle Creek, MI
Bob and Nancy Brownee, Battle Creek, MI
Keith Walback, Battle Creek, MI
Bruce Rohrer, Battle Creek, MI
Shelia Loston, Battle Creek, MI

MDS Patient Registry

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

The MDS Foundation
PO Box 353
Crosswicks, NJ 08515
Phone: 1-800-MDS-0839 within the US
Outside the US only: 1-609-298-6746
Fax: 1-609-298-0590

MDS Foundation Plans 2005 Initiatives

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

- CME Awareness Program
- MDS Foundation Charity Golf Tournament
  August 1, 2005
  Supported by grants from:

- MDS Practice and Treatment Registry
- The International Morphology Working Group
- MDS Patient’s Quality-of-Life Forums
- Transfusion Burden Initiative
  Supported by a grant from:
- Patient Sero-Therapy Registry
  Supported by a grant from:

Patients: Your Help is Needed!

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

About the Foundation

The Myelodysplastic Syndromes Foundation was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS. Until the Foundation was set up, no formal working group had been devoted to MDS. During the past decade we have conducted seven international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, and France. The Eighth International Symposium is being held May 12–15, 2005 in Nagasaki, Japan. A major Foundation effort is our international information network. This network provides patients with referrals to Centers of Excellence, contact names for available clinical trials, sharing of new research and treatment options between physicians, and extension of educational support to both physicians and patients.

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

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

Our Website

The MDS Foundation Web page is for healthcare professionals, patients, and other interested people. The Professional Forum and the Patient Forum are integral parts of our Web site. The Website is constantly being updated to better serve the needs of our patients, their families, and the physicians who treat them. We welcome your suggestions. Please visit us at http://www.mds-foundation.org
International Clinical Trials: An Update

The following trials are current as of the date of this newsletter. We will update this 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: 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).
- Phase II: Patients with the disease receive the drug at doses that will be similar to those used in the earlier phase. The purpose of this trial is to determine effectiveness and the drug provides more information about its safety.
- Phase III: The drug is tested alone 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 through routine usage.

Some trials—screening studies evaluating supportive care or prevention—are not conducted in phases. In these trials a group following a certain disease combating strategies, 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”

Other U.S. Trials

Barbara Ann Karmanos Cancer Institute, Detroit, MI.


Barbara Ann Karmanos Cancer Institute, Detroit, MI.

POG A2971: Treatment of Children with Down Syndrome and Acute Myeloid Leukemia, Myelodysplastic Syndrome, or Myeloproliferative Disorder. Contact: Jeffrey Taub, MD. Phone: 313-963-2533.


Cancer Institute Medical Group, Los Angeles, CA.

Phase I/IIa Study of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes. Contact: Lawrence D. Pro, MD. Phone: 310-349-2616.

Case Western Reserve University, Cleveland, OH.


Case Western Reserve University, Cleveland, OH.

CWRU-01-504. Phase II using umbilical cord blood to evaluate the efficacy of transplantation to treat aplastic anemia and myelodysplastic syndromes patients. Eligible patients must have an HLA-identical sibling. Contact: Mary J. Laughlin. Phone: 216-844-8069.

Cedars-Sinai Medical Center, Los Angeles, CA.

2287. Phase II Trial of Paricalcitol in Myelodysplastic Syndromes to determine if an oral, relatively non-toxic, novel vitamin D analog plus best supportive care for patients with MDS. Contact: H. Phillip Koeffler, MD. Phone: 310-231-2182.

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 in patients with MDS. Patients will receive oral administration of paricalcitol in increasing doses. Contact: H. Phillip Koeffler, MD. Phone: 310-423-4609.

Clinical Trials: An Update

Click on “Finding Clinical Trials” and

Click on “Search for Clinical Trials” and

Click on “Type of Cancer” and type in “myelodysplastic syndromes.”

Hit search

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

ADVANCED CANCERS: A NEW TRANSPLANT METHOD

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

Novartis.

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

An open-label Phase II Trial of PKC412 Monotherapy in Patients with Acute Myeloid Leukemia and Patients with Myelodysplastic Syndrome PKC412104. Patients who agree to participate in this trial will be screened for the FLT3 mutation. If positive, they will have a physical exam, blood test, EKG, chest x-ray, bone marrow aspirate and a pregnancy test.

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

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

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

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


Dana-Farber Cancer Institute, Boston, MA. Phase I Study of Vaccination with Lethally Irradiated, Autologous Auto Myeloid Leukemia Cells Concomitant with Mediated Gene Transfer to Secrete Human Granulocyte-Macrophage Colony Stimulating Factor in Patients with Advanced Myelodysplastic Syndromes—myelogenous Leukemia. This is a study to determine the feasibility of preparing lethally irradiated autologous myeloblast progenitor cells engineered by adeno-associated 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 myeloblast progenitor cells engineered by adeno-associated gene transfer to secrete GM-CSF in patients with advanced myelodysplasia or acute myelogenous leukemia. Contact: Ilene Galinsky. Phone: 617-635-9930.

Duke University Medical Center, Durham, NC. Phase II trial to assess the value of non-myectabolite ablative therapy (mini bone marrow transplant) for patients with aplastic anemia or myelodysplastic syndromes. Patients must have severe disease to be either relapsing disease or have a matched sibling, mismatched family member, or large cord blood unit found for use on our trial. Contact: David A. Rizzieri, MD at Rizzie003@mc.duke.edu.


Fox Chase, BMT Program, Philadelphia, PA. 3297. Phase II trials using fludarabine-based regimen to evaluate the efficacy of mini-allogeneic stem cell transplantation to treat myelodysplastic syndromes. Eligible patients must have HLA identical donor available, be under age 70 and platelet < 75,000. Combination of 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: Annette Sagree, MD at 215-662-5122.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCR #1297. Radiolabeled BC8 (anti-CD-45) Antibody Combined with Cyclophosphamide and Total Body Irradiation Followed by HLA-Matched Related or Unrelated Stem Cell Transplantation as Treatment for Advanced Acute Myeloid Leukemia and Myelodysplastic Syndrome. Phase II trial to determine the efficacy of mini-allogeneic stem cell transplantation (SCT) and disease-free survival) and toxicity of a regimen of cyclophosphamide, TBI plus the maximum tolerated dose of labeled BC8 (anti-CD45) antibody in patients with AML.
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. 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-risk or less advanced-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 #1937. A Phase I/II, two-arm, multicenter, dose-escalation study of LB5689 administered intravenously on two dose schedules in adult patients with advanced hematologic malignancies. Inclusion criteria: Patients with a cytopenopthologically confirmed diagnosis of AML, MDS, RAEB, RAEB-T, 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 must be cytogenopthologically confirmed diagnosis of AML, MDS, RAEB, RAEB-T who are previously untreated but due to age, poor prognosis, or concurrent medical conditions are considered inappropriate candidates for standard induction therapy, or those who refuse standard induction therapy. Contact: Wendy Hodapp. Phone: 813-745-1708.


Johns Hopkins Oncology Center, Baltimore, MD. J0051. Phase I dose de-escalation to minimal effective pharmacologic dose trial of sodium phenylbutyrate in combination with 5-azacytidine in patients with myelodysplastic syndromes. Contact: Tianna Dauses. Phone: 410-502-7110.


Johns Hopkins Oncology Center, Baltimore, MD. J0950. Phase I dose de-escalation to minimal effective pharmacologic dose trial of sodium phenylbutyrate in combination with 5-azacytidine for the treatment of myelodysplastic syndromes. Contact: Dr. B. Douglas Smith. Phone: 410-614-5068.


Johns Hopkins Oncology Center, Baltimore, MD, J0252. Phase II study of the farnesyl transferase inhibitor Zarnestra in combination with daunorubicin and cytarabine in patients with myelodysplastic syndrome. Contact: Dr. Steven Gore. Phone: 410-955-6781.

Los Angeles Hematology and Oncology Assoc., Los Angeles, CA. Phase II study of arsenic trioxide in combination with daunorubicin in patients with MDS. Contact: C. Gota, MD. Phone: 818-409-1015.

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

MD Anderson Cancer Center, Houston, TX. Randomized, Open-Label, Phase III Trial Of Decitabine (5-AZA-2’-Desoxycytidine) Versus Conventional Chemotherapy Regimen in Adults With Advanced-Stage Myelodysplastic Syndrome. Contact: Jean-Pierre Issa, MD. Phone: 713-745-2200.

MD Anderson Cancer Center, Houston, TX. Safety and Efficacy Trial of Bevacizumab: Anti-VEGF Humanized Monoclonal Antibody (NSD 754865) Therapy for Myelodysplastic Syndrome (MDS). Contact: Jorge Cortes, MD. Phone: 713-745-5783.

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

MD Anderson Cancer Center, Houston, TX. Multicentre Phase III Study Of Continuous Oral Administration Of SOCH 66336 In Patients With Advanced Myelodysplastic Syndrome, Acute Myelogenous Leukemia, Chronic Myelogenous Leukemia. Contact: Jorge Cortes, MD. Phone: 713-745-5783.

MD Anderson Cancer Center, Houston, TX. Phase II study of Intravenous Homoharringtonine in Chronic Myelogenous Leukemia (CML). Contact: Jorge Cortes, MD. Phone: 713-745-5783.

MD Anderson Cancer Center, Houston, TX. Therapy of Hypereosinophilic Syndrome. Polychemotherapy (Ara-C), Alcyon CML or CMML with PDGF-R Fusion Genes, or Mucocystosis with Gleevec (STI571). Contact: Jorge Cortes, MD. Phone: 713-745-5783.

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

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


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: 713-782-1701.

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 in patients with severe refractory anemia. Eligible patients must have RA or RARS and low blood counts. Contact: Jeffrey Moldrem, MD. Phone: 713-745-4820.

MD Anderson Cancer Center, Houston, TX. ID00-116. Pilot study of RFG0122 or Dapsiposide (NSC001076) for adult patients with advanced hematologic disorders. Contact: Virginia Klimek, MD. Phone: 212-639-6519.


Memorial Sloan-Kettering Cancer Center, New York, NY. 00-116. Pilot study of RFG0122 or Dapsiposide (NSC001076) for adult patients with advanced hematologic disorders. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

Mount Sinai Medical Center, New York, NY. Phase II/II Study Of Dipeptide (Depsipeptide) For Use As A Supportive Care For The Treatment Of Myelodysplastic Syndromes (MDS). Contact: Lewis Silverman, MD. Phone: 212-241-5520.

Mount Sinai Medical Center, New York, NY. Phase II clinical-laboratory study of the histone deacetylase (HDA) inhibitor MS-275 in combination with 5-Azacytidine (5-aza-2’-deoxycytidine). Contact: Virginia Klimek, MD. Phone: 212-639-6519.

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

National Heart, Lung, and Blood Institute, Bethesda, MD. 01-H-0162. Stem Cell Transplantation for Older Patients with Myelodysplastic Syndrome. If you are 55 to 75 years of age and have an HLAmatched brother or sister donor to participate in this trial. Contact: Laura Wisch, MD. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 04-H-0026. Randomized Trial of Dacituzumab versus ATG for Myelodysplastic Syndrome. 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 HLAmatched 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, MD. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 04-H-0026. Randomized Trial of Dacituzumab versus ATG for Myelodysplastic Syndrome. 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 HLAmatched brother or sister donor to participate in this trial. Contact: Laura Wisch, MD. Phone: 301-402-0797.
years of age and have been diagnosed with advanced myelodysplastic syndrome, you may be eligible for a clinical trial of a transplant procedure that evaluates a new method for hematopoietic stem cell transplantation using Non-Myeloablative Conditioning—A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 8343. Prolonged Mycophenolate Mofetil and Truncated Cyclosporine Postirradiation suppression to Reduce Life-Threatening GvHD. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Oregon Health & Science University, Portland, OR. 8345. Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of myelodysplasia. Bone marrow will be obtained at 16 weeks and then at the end of the study. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

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. 8348. Phase III trial of Trisenox in combination with low dose Ara-C for the treatment of high-risk MDS and poor prognosis AML. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. Phase II trial of darbepoetin alfa in patients with myelodysplastic syndrome, you may be eligible for a clinical trial of a transplant procedure that evaluates a new method for hematopoietic stem cell transplantation using Non-Myeloablative Conditioning—A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.


Diabetic Retinopathy Treatment with Retalin® (anti-VEGF antibody). Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Prolonged Mycophenolate Mofetil and Truncated Cyclosporine Postirradiation suppression to Reduce Life-Threatening GvHD. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Diabetic Retinopathy Treatment with Retalin® (anti-VEGF antibody). Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Princess Alexandra Hospital, Queensland.

A multicenter randomized open-label parallel group phase II 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.

The Newcastle Mater Misericordiae Hospital, New South Wales.

AUSTRALIA

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

Washington University School of Medicine, St. Louis, MO. Multicenter randomized open-label parallel group phase 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: Alisa Ruddell. Phone: 314-454-4066.

Washington University School of Medicine, St. Louis, MO. This study seeks individuals with bone marrow failure. Participants are asked to submit a sample of blood for gene and telomere analysis. Researchers are investigating the t(10;11) gene found on chromosome 3. Participants are also asked to submit their medical and family history information. This information is used to make up a profile for the participants among the clinical features and the gene and telomere analysis. Contact: Jennifer Ivanovich, MS. Phone: 314-454-6307.

Western Pennsylvania Cancer Institute, Pittsburgh, PA.


University of Texas Health Science Center at San Antonio, Texas, TX. Phase IIa Study of Liposome-Encapsulated Doxorubicin (optional) followed by chemotherapy. Contact: Natale Callander, MD. Phone: 210-617-5300 Ext. 4720.

University of Texas, UT Health Science Center, San Antonio, TX. Randomized, double-blind, placebo controlled trial assessing the safety and efficacy of thalidomide in 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% 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 Waidrop. Phone: 972-566-7790.

University of Chicago, Chicago, IL. Phase II study of an oral VEGF receptor tyrosine kinase inhibitor (PTK767/292/22554B) (IND # 056570. NSC # 719355) in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Chicago, Chicago, IL. 13172B. Phase I/II Study 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 (PTK767/292/22554B) (IND # 056570. NSC # 719355) in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Louisville, Louisville, KY. #541.02. Pilot study of arsenic trioxide in patients with MDS. Contact: Shubhada M. Jagasia, MD. Phone: 615-332-4752.

Wake Forest University School of Medicine, Winston-Salem, NC. CCCFWU-29293. Orally active Vitamin D in Low Back pain patients with Myelodysplastic Syndromes. Contact: Shubhada M. Jagasia, MD. Phone: 615-332-4752.

The Alfred Hospital, Victoria, 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: Andrew Spencer. Phone: +61 3 9876 3199.

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

Texas Oncology Medical City Dallas Hospital, Dallas, TX. SMC-101-1020. Open-label, prospective, stratified, randomized, controlled, multicenter, phase II/III study of the impact of Thymoglobulin on treatment transplants of patients with myelodysplastic syndrome. This protocol evaluates Thymoglobulin therapy for 4 days. Eligibility includes low risk MDS (RA, RAEB <10%), IPSS <1.5, transplanted with chemotherapy allowed. Contact: Ronda Waidrop. Phone: 972-566-7790.
The Royal Bournemouth Hospital. Dose-reduced versus standard condition maintained by alogenic stem cell transplantation in patients with MDS or aMML. A randomized phase III study. Contact: Nicolas Kröger, MD. 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: +35-30-8445-5903.


University Hospital Campo Alegre, Porto. A multicenter randomized, double-blind, parallel-group, Phase III trial of subcutaneous vorinostat in patients with advanced myelodysplastic syndrome (MDS) who are not eligible for an allogeneic hematopoietic stem cell transplantation. Contact: Dr. D. Ferreira. Phone: +351 22 2044 6640.
Myelodysplastic syndromes can be difficult to diagnose and treat. It is important for both patients and their families to know that optimal treatment is available and that quality-of-life can be enhanced. If you would like information about treatment options, research, or quality-of-life, we would be glad to help. The Foundation offers a variety of patient services, including preferential referrals to the Foundation’s MDS Centers of Excellence. Please contact us at: 1-800-MDS-0839 (phone) or 609-298-0590 (fax). Outside the US please call: 609-298-1035.

You can visit our website at http://www.mds-foundation.org.
MDS Educational Resources for Clinicians

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

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

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

When ordering, use code: PAN02023

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

A NEW CME PROGRAM AVAILABLE IN CD-ROM FORMAT


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

PATIENT INFORMATION AND EDUCATIONAL MATERIALS AVAILABLE FROM THE MDS FOUNDATION

A. Understanding Myelodysplastic Syndromes: A Patient Handbook

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

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

Published by The Myelodysplastic Syndromes Foundation

C. Patient Diary

Published by The MDS Foundation

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

Supported by a grant from Celgene Corporation.

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

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

The John Peter Murphy Research Fund

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

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

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

Patient Services

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

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

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

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

Call here for: Outreach, development and administrative inquiries.

Operations Center
50 Fullerton Ct., Suite 200
Sacramento, CA 95825
Phone: (916) 641-7800
Toll-free: (877) AIR LIFE (247-5433)
Fax: (916) 641-0600

Call here for: Passenger/pilot inquiries
YY?: Not available, but we can use a relay operator.

Website: www.AirLifeLine.org
E-mail: Info@AirLifeLine.org
Administrator: Randy Quast, President & Volunteer Pilot

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

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

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

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

Many families are affected by living with the reality of MDS. There is an extraordinary way to contribute to the MDS Foundation and support our mission of working as a resource for patients, families, and healthcare professionals. A commitment to donate to the Foundation on occasions of loss, birthdays and anniversary remembrances can be made. Honor your friends or family members on these occasions with a donation, and The MDS Foundation will send an acknowledgment to the recipient, recognizing the occasion.

The MDS Foundation is grateful for community support. Our work as a non-profit organization depends on public funding. If you would like to contribute in this way, please write to us at: 36 Front Street, P.O. Box 353 Crosswicks, NJ 08515 or call us at 1-800-MDS-0839.

A Living Endowment donation has been made in honor of:

**Lokey Johnson**

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

A Living Endowment donation has been made in honor of:

**Albert Nase’s 80th Birthday**

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

Suzanne Fleischman Memorial Fund for Patient Advocacy

New donations have been made by:

Edward Fleischman, Prescott, AZ
Eugene and Eloise Fox, Kensington, CA

In Memorium

A memorial fund has been established in the name of

**Mr. George Allen**

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

- Joan Dillard
- Howard, MA
- Angela and Elizabeth Dibble
- Sanford, ME

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mrs. Jackie Anderson**

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

- James and Suzanne Greenstreet
- Alexandria, VA
- Marcia Hertogard
- Denver, CO
- Robert and Amelie Ehrman
- Joppa, MD

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mrs. Vivian Balick**

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

- Gashley and Sandy Goldwater
- Cherry Hill, NJ

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. Robert James Beams**

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

- James F. Higgins
- Freehold, NJ
- Kenneth and Lisa Rossi
- Freehold NJ
- Thomas and Nancy Bubby
- Marlboro, NJ
- Philip and Catherine Vourtsis
- Marlton, NJ
- Social and Recreational Committee
- Marlton, NJ

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Ms. Julie Bernard**

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

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

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. Raymond Blair**

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

- Hazel B. Davis
- Scarborough, ME
- The Times Record
- Brunswick, ME
- Bruce W. Smith
- Cumberland, ME
- Virginia M. Wright
- Cumberland, ME

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. Roger A. Brown**

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

- Bud and Mary Alice Thomas
- Danville, CA

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. Ed R. Burle**

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

- Ron, Larry and Jerry Burle, Hixson, TN

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Ms. Phyllis Carter**

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

- Bonnie Cooper
- League City, TX
- Tachi Shei Lai
- Plano, TX

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mrs. Carol Cazier**

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

- Claire T. Cazier
- Los Angeles, CA
- David and Jacqueline Smiley
- Corona Del Mar, CA
- Edward Cazier
- Los Angeles, CA
- Bobbie and Patricia Williamson
- Corona Del Mar, CA
- Robert and Isabu Kubojaishi
- Ranch Palos Verdes, CA
- Alan and Mary Andrews
- Newport Beach, CA

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. Lawrence Conn**

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

- Tim and Leslie Loveless
- Corona, CA
- Coyen Berman
- Corona, CA
- Zoch and Mary E. Knight
- Corona, CA
- Donald and Clark Tula
- Corona, CA
- Eugene J. Emer
- Carmel, CA

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. Edward J. Coyne**

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

- Donald F. Burke
- Brick, NJ
- Mary Skirkey
- Point Pleasant, NJ
- Robert McCabe
- Point Pleasant, NJ

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. Warren Deming**

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

- William and Jo Ann Bay
- Lexington, KY
- Jacqueline Coulombre
- Acushnet, MA
- Berengere M. Bairos
- Acushnet, MA

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Mr. R. Burle**

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

- Ron, Larry and Jerry Burle, Hixson, TN

**Skibbins Greenhouses**

A memorial fund has been established in the name of

**Ms. Phyllis Carter**

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

- Bonnie Cooper
- League City, TX
- Tachi Shei Lai
- Plano, TX

**Skibbins Greenhouses**
A memorial fund has been established in the name of Mrs. Mary Lou Eekhoff Donations have been made in Mrs. Eekhoff’s memory by:
  George and Marilyn Eekhoff, Belmont, CA
A memorial fund has been established in the name of Mr. Sam Friedman Donations have been made in Mr. Friedman’s memory by:
  William M. Friedman, Lakewood, CT
A memorial fund has been established in the name of Mrs. Jennifer Gallagher-Welch Donations have been made in Mrs. Gallagher-Welch’s memory by:
  Carolyn B. Carlson, Osceola, FL
A memorial fund has been established in the name of Mr. Roger D. Griswold Donations have been made in Mr. Griswold’s memory by:
  Ellen Gregory Canfield, OH
  Robert Mulcahy, FL
  Mary and Patricia Giesler Dayton, OH
  Deborah Hawkins Enon, OH
  Dr. Joseph P. Gallagher Baldrick, OH
  Norma Hall Enon, OH
  William J. Pegel Saint Albans, TX
  Dr. Marti O’Brien San Antonio, TX
  Gary J. Kepley Xena, WI
  Mary Jo Kepley Xena, WI
  Melissa Beasley and Wightt-Patocken Air Force Base OH
  McCormick and O’MALLEY Insurance Agency Springfield, OH
A memorial fund has been established in the name of Dr. Joseph Guittfried Donations have been made in Dr. Guittfried’s memory by:
  Lois A. Heish, Altamonte Springs, FL
  Nancy Livers Margolis New York, NY
  Eileen Livers New York, NY
  Robert and Phoebe Liss Great Neck, NY
  Eric and Jan Auer Great Neck, NY
A memorial fund has been established in the name of Mr. Bob Hagen Donations have been made in Mr. Hagen’s memory by:
  Jan Rosen Eureka, CA
  Judy Mullen, Marlboro, CA
A memorial fund has been established in the name of Ms. Lorraine Halasiewicz Donations have been made in Ms. Halasiewicz’s memory by:
  Helen Szymanski Caper Mill, NJ
  Alfreid Sokolowski Java River, NJ
A memorial fund has been established in the name of Mr. Norman Halpem Donations have been made in Mr. Halpem’s memory by:
  Harold and Joyce Tilleran, Wayne, PA
A memorial fund has been established in the name of Ms. Hazel A. Klush Donations have been made in Ms. Klush’s memory by:
  Charles and Susan Chopack Barrington and Patricia Thomas Farmington Hills, MI
  Beth and Steven Chopack Waterford, MI
A memorial fund has been established in the name of Mr. John Paul Johnson Donations have been made in Mr. Johnson’s memory by:
  J. Haroldt Boyd Monroe, GA
  Lawson and Rose Sewell Lagrange, GA
A memorial fund has been established in the name of Mr. Joseph Kotelicki Donations have been made in Mr. Kotelicki’s memory by:
  Tammy and Michael Kotelicki, Vienna, VA
A memorial fund has been established in the name of Reverend Lawrence Larsen, Jr. Donations have been made in Reverend Larsen’s memory by:
  Jerome and Margaret Grubau, Bainbridge, IA
A memorial fund has been established in the name of Mr. Charles Lee Donations have been made in Mr. Lee’s memory by:
  Christopher and Catherine Engel, Chatham, NJ
A memorial fund has been established in the name of Mrs. Florence Littlesjohn Donations have been made in Mrs. Littlesjohn’s memory by:
  William Frank, San Francisco, CA
A memorial fund has been established in the name of Mrs. Loma Marie Donations have been made in Mrs. Marie’s memory by:
  Lynne O’Brien, Ottawa, Canada
A memorial fund has been established in the name of Mr. George Manocchio Donations have been made in Mr. Manocchio’s memory by:
  James and Deborah Homer, Sylvania, OH
A memorial fund has been established in the name of Mrs. Joya Mahshur Donations have been made in Mrs. Mahshur’s memory by:
  Henry and Norma Moody James and Conrie Cory Newaven, GA
A memorial fund has been established in the name of Mr. Jack McCullough Donations have been made in Mr. McCullough’s memory by:
  Lynn and Kathryn Bondi Memphis, TN
  Reiner and Diane Church ffton, TN
A memorial fund has been established in the name of Mrs. Barbara Claire Meland Donations have been made in Mrs. Meland’s memory by:
  Norman and Laura Allison, Marlton, NJ
A memorial fund has been established in the name of Mrs. Virginia Mittler Donations have been made in Mrs. Mittler’s memory by:
  Walter and Josephine Guelstein Livingston, NJ
  Patricia McCord, PA
A memorial fund has been established in the name of Mrs. Shirley Millard Donations have been made in Mrs. Millard’s memory by:
  Glenn Millard, Whitefish, MT
A memorial fund has been established in the name of Mrs. Janet Mullikin Donations have been made in Mrs. Mullikin’s memory by:
  Kneal Ed and Estine Morton Brookhaven, MS
A memorial fund has been established in the name of Mrs. Norma Rolando Donations have been made in Mrs. Rolando’s memory by:
  Angelo R. Rolando Robbert and Nelia Lampliti Newington, CT
  Rocky Hill, CT
  Church of St. Elizabeth Seton Rocky Hill, CT
A memorial fund has been established in the name of Dr. Sierra Donations have been made in Dr. Sierra’s memory by:
  Tracy Lund Steve and Kim Rowe Fishier, IN
A memorial fund has been established in the name of Mrs. Myrtle W. Slade Donations have been made in Mrs. Slade’s memory by:
  Jeffrey and Sarah Kowalak Robert C. Wilson Sr.
  Toshiy, TX
  Pass Rock
A memorial fund has been established in the name of Mr. Michael Stabile Donations have been made in Mr. Stabile’s memory by:
  Hurley and Sally Ryan		
  Robert C. Wilson, Sr.
  Hendersonville, NC
A memorial fund has been established in the name of Mr. Richard Valicenti Donations have been made in Mr. Valicenti’s memory by:
  Leila and Pat Silka Pleasant Hill, CA
A memorial fund has been established in the name of Mr. Aaron Wegewaer Donations have been made in Mr. Wegewaer’s memory by:
  Caucasian Wegewaer
  Plantation, FL
A memorial fund has been established in the name of Mr. Russ Woodfield Donations have been made in Mr. Woodfield’s memory by:
  Dean C. Matthews Rio Verde, AZ
  H. Wayne Roberts Wichita, KS
  Nelson C. Boyer
  Michael and Marilyn Crisci Somerville, CA
  T. Carl and Dona Badgett Houston, TX