Spring 2003 • Volume 7, Issue 2

THE MDS NEWS

The Newsletter of The Myelodysplastic Syndromes Foundation

Mia Hamm: Leading the Charge

An interest in sports is not needed to recognize the name of Mia Hamm. Mia made headlines and worldwide news as she and her teammates won the Gold Medal for women's soccer at the 1996 Olympics held in Atlanta, Georgia. Besides her leading role in the international sports circuit, Mia is also a leader in the campaign against bone marrow diseases. In 1999, she formed The Mia Hamm Foundation, a non-profit, national organization which raises funds for research and awareness of bone marrow diseases.

In 1997, Mia's brother, Garrett, died from complications related to aplastic anemia. Since then, Mia has translated her loss into action, calling upon many individuals to make and renew commitments to bone marrow research and meeting the needs of these patients. Recently, Mia participated in the joint annual meeting of the Society for Blood and Marrow Transplantation and the International Bone Marrow Transplant Registry that was held January 20 through February 3, 2003, in Keystone, Colorado. At this meeting of researchers and clinicians, Mia shared Garrett's story, her personal thoughts, and her current activities:

From 3:45 to 7:00 a.m. today, Dr. Molldrem and I were talking to television stations from across the country, discussing the need for people to enter the bone marrow registry. What fascinates me is how little people know about the procedure for bone marrow donation. It's probably the easiest of all transplant procedures, yet people are reluctant to register.

I am grateful to people like yourselves that are out there every day trying to find new ways to treat bone marrow-related diseases, like that which my bother had. I was with Garrett the day when Dr. Molldrem walked into the room broken-hearted and crying, telling my brother there was nothing else he could do for him that his only chance of survival was a bone marrow transplant and that the risk associated with transplantation was extremely high. Despite the risk, transplantation was worth a try for Garrett and for us. On behalf of myself and my family, I want to thank Dr. Molldrem for everything he did for Garrett. I also want to thank Dr. Henslee-Downey, who did the transplant procedure, for everything she and her staff did for my family.

For my brother to fight for his life everyday and for my family to watch the struggle was very difficult. Finally, we told Garrett that it was okay to let go, that he had done everything in his power to live another day. Garrett's allowing us to let him go was probably the hardest part for him.

A charity game is held in Milwaukee in support of young children that are at the University of Wisconsin, Milwaukee Children's Hospital. At this event, bone marrow recipients meet their donors. The first meeting between recipient and donor is one of the most emotional experiences you could ever witness. Certainly, recalling these moments takes away any doubt I might have about doing something for someone else, like getting up at 2:30 a.m. in order to meet with television crews. To see young children burdened with bone marrow-related diseases hug their loved ones one more time is worth all of the effort.

(continued on page 2)

Contents

I want to say to the researchers and physicians here at this meeting that you are making a difference—I hope I am too. I am encouraged whenever I see transplant recipients embracing their families and continuing in life. It can be a great story.

Thank you again for inviting me to share with you today. Continue diligence in all your work and may these efforts lead to continued success. Thank you once again.

Along with her teammates, Mia captured the 1996 Olympic Gold Medal for women's soccer. Mia has led the United States to World Championship at the Women's Cup and is a five-time winner of the United States Soccer Federation Female Athlete of the Year. She is the first player from the United States to score 100 career goals and, in 1999, became the world's leading goal scorer in international men's and women's soccer competition. More information about Mia and The Mia Hamm Foundation can be found at the website www.miafoundation.org.

Be a Bone Marrow Donor

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

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

Patient Services

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

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

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

RESOURCE DATABASE INFORMATION:

Agency Name: **AirLifeLine**

National Office
5775 Wayzata Blvd., Suite 700
Minneapolis, MN 55416
Phone: (952) 582-2980
Toll-free: (877) 727-7728
Fax: (952) 546-5885
Call here for: Outreach, development and administrative inquiries

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

TYY: Not available, but we can use a relay operator.

Website: www.AirLifeLine.org

E-mail: Info@AirLifeLine.org

Administrator:
Randy Quast, President & Volunteer Pilot

Contact person for agency information:
Ginger Buxa, Director of Outreach
Ginger@AirLifeLine.org or (877) 727-7728

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

Services Provided: AirLifeLine coordinates the following services:

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

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

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

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

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

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

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

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

Cost/Fees: None, but donations accepted

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

Target group: Anyone with financial need who needs air transportation

Age Range: All

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

Languages: English and Spanish

If you need more information for your resource database or website listing, please contact:
Ginger Buxa, Director of Outreach
(877) 727-7728, E-Mail: Ginger@AirLifeLine.org

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.

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

Barbara Ann Karmanos Cancer Institute
Wayne State University
Detroit, Michigan
Esteban Abella, 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. Phillip Koeffler, MD

City of Hope National Medical Center
Duarte, California
Stephen J. Forman, MD

Dana-Farber Cancer Institute
Boston, Massachusetts
Richard M. Stone, MD

Cleveland Clinic Foundation
Taussig Cancer Center
Cleveland, Ohio
Jaroslaw Maciejewski, MD

Duke University
Duke University Medical Center
Durham, North Carolina
Carlos M. deCastro, MD

Fred Hutchinson Cancer Research Center
Seattle, Wasington
H. Joachim Deeg, 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
Rochester, Minnesota
Louis Letendre, MD

MCP Hahnemann University
Philadelphia, Pennsylvania
Emmanuel C. Besa, MD

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

New York Medical College/
Westchester Medical Center
Zalmen A. Arlin Cancer Center
Valhalla, NY
Karen Seiter, MD

New York Presbyterian Hospital
Columbia College of Physicians and Surgeons
New York, New York
Charles Hesdorffer, 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
Grover Bagby, MD

Roswell Park Cancer Center
Buffalo, New York
James Slack, MD

Rush Cancer Institute
Rush–Presbyterian– St. Luke's Medical Center
Chicago, Illinois
Azra Raza, MD

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's Childrens' Research Hospital
Memphis, Tennessee
Gregory Hale, MD

Tufts University School of Medicine
New England Medical Center
Boston, Massachusetts
Kenneth Miller, MD

University of Alabama at Birmingham
Comprehensive Cancer Center
Birmingham, Alabama
Peter Emanuel, MD

University of Arizona
Arizona Cancer Center
Tucson, Arizona
Alan F. List, MD

University of Chicago
University of Chicago Medical Center
Chicago, Illinois
Richard A. Larson, MD

University of Nebraska
University of Nebraska Medical Center
Omaha, Nebraska
Julie Vose, 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
Hussain Saba, MD, PhD

University of Texas
MD Anderson Cancer Center
Houston, Texas
Elihu H. Estey, MD

Washington University School of Medicine
Barnard 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. Shadduck, MD

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

OUTSIDE THE UNITED STATES

A.C. Camargo Hospital – Cancer Center
Sao Paulo, Brazil
Luiz Fernando 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 Sollievo Della Sofferenza Hospital
S. Giovanni Rotondo Italy
Pelligrino Musto, MD

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

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

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

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

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

Jagiellonian University
Collegium Medicum
Krakow, Poland
Aleksander Skotnicki, MD, PhD

Johann Wolfgang Goethe University
Frankfurt Main, Germany
Wolf-Karsten Hofmann, MD

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

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

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

Ludwig Maximilians University
Munich, Germany
Torsten Haferlach, MD

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

Odense University Hospital
The University of Southern Denmark
Odense, Denmark
Gitte Birk Kerndrup, MD

Patras University Hospital
Patras, Greece
Nicholas C. Zoumbos, MD

Peter MacCallum Cancer Institute
University of Melbourne
East Melbourne, Victoria, Australia
John F. Seymour, MD

Rabin Medical Center – Hasharon Hospital
Tel Aviv University – Sackler School of Medicine
Petah-Tikva, Israel
Moshe Mittelman, MD

Saitama Medical School Hospital
Morohongo, Iruma, Japan
Akira Matsuda, MD

Services D'Hematologie Hôpital Cochin
University Paris V Service
Paris, France
Prof. Francois Dreyfus, PU-PH

Service des maladies de Sang
Centre Hospitalier
Universitaire of Lille
Lille, France
Prof. Pierre Fenaux

St. Johannes Hospital
Heinrich-Heine University
Duisburg, Germany
Carlo Aul, MD, PhD

The Royal Bournemouth Hospital
Bournemouth, UK
Prof. Terry J. Hamblin

Tokyo Medical College
Tokyo, Japan
Kazuma Ohyashiki, MD

University of Aarhus
The University Hospital
Aarhus, Denmark
Professor Johan Lanng Nielsen

University of Athens
Laikon Hospital
Athens, Greece
Nora Viniou, MD

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

University of Dundee Medical School
Dundee Teaching Hospital
Dundee, Scotland
David T. Bowen, MD

University of Florence
Azienda DSP Careggi
Florence Italy
Alberto Grossi, MD

University of Freiburg Medical Center
Freiburg, Germany
Michael Luebbert, MD

University Hospital of Innsbruck
Innsbruck, Austria
Prim. Univ. Prof. Dr. Franz Schmalzl

University of Nijmegen
University Hospital St. Radboud
Nijmegen, The Netherlands
Theo J.M. deWitte, MD, PhD

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

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

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

University of Vienna
Vienna, Austria
Peter Valent, MD

MDS 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
When ordering, use code PAO50203

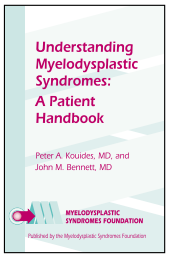
This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse environmental and genetic factors, and efficient modalities of supportive care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

A NEW CME PROGRAM AVAILABLE IN CD-ROM FORMAT

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

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

PATIENT INFORMATION AND EDUCATIONAL MATERIALS AVAILABLE FROM THE MDS FOUNDATION



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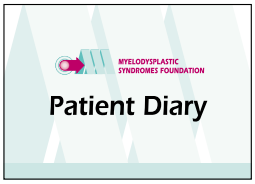

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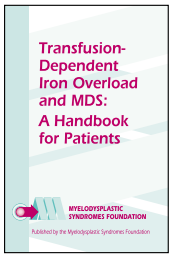

C.

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

Patient Advocacy Groups Are Being Established by the MDS Foundation

The MDS Foundation has been working to develop a strategy for setting up patient groups nationwide. We have now completed this process and would like to have your help.

These volunteers are providing local support to MDS patients and their families, developing new information for patients, and planning fund raising programs to support these activities. Any member of the Foundation, patients, friends and family members are invited to join with us to move these projects forward.

Please contact the Patient Liason: 800-MDS-0839 to volunteer.

Your help is needed!!

B. Patient Diary
Published by
The Myelodysplastic Syndromes Foundation

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

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

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
Toll free: 888-597-7674
Tel: 847-433-3313 Fax: 847-433-4599
E-Mail: help@bmtinfonet.org
Web: www.bmtinfonet.org

International Clinical Trials: An Update

The following trials are current as of the date of this newsletter. We will update the list in The MDS News each quarter. If you are a treating physician who would benefit from any such study, you may want to contact the appropriate institution. If you are an MDS patient, you may wish to discuss a trial with your primary treating physician to see if you qualify as a candidate.

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

A clinical trial falls into one of four phases:

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

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

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

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

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

U.S. Trials

NATIONAL CANCER INSTITUTE TRIALS*

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

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

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

NEW CLINICAL TRIALS IN MDS

Celgene Corporation will initiate two new MDS Trials in June 2002 in cooperation with the MDS Foundation. If you would like more information please call the Foundation at 800-MDS-0839 or visit our web site and e-mail us. More information concerning these trials will be posted on our web site within the next few weeks.

CC-5013-MDS-002: "A Multicenter, Single-arm, Open-label Study of the Efficacy and Safety of CC-5013 Monotherapy in RBC Transfusion-dependent Subjects with Myelodysplastic Syndromes"

CC-5013-MDS-003: "A Multicenter, Single-arm, Open-label Study of the Efficacy and Safety of CC-5013 Monotherapy in Red Blood Cell Transfusion-dependent Subjects with Myelodysplastic Syndromes Associated with a Del (5Q) Cytogenetic Abnormality"

Novacea. DN101-003. This study is a research study for patients with a blood disorder called myelodysplastic syndromes (MDS) who are dependent on repeat blood transfusions. It involves treatment with DN-101 (a formulation of calcitriol designed specifically for oncology and hematology) that is being investigated to determine if it may improve symptoms of fatigue and reduce the need for repeat blood transfusions.

Results of previous laboratory and clinical studies have suggested that calcitriol may be useful in treating MDS. Up to 46 patients with low- and intermediate-1 risk MDS who are red blood cell transfusion dependent because of severe anemia will be enrolled in this study at 10 research centers in the United States.

For more information, please go to www.novacea.com.

Other U.S. Trials

Barbara Ann Karmanos Cancer Institute. D-696. Allogenic and syngenieic marrow transplantation in patients with acute non-lymphocytic leukemia. Contact: Jared Klein, MD. Phone: 313-966-7434.

Cleveland Clinic Foundation. IRB5777. A Phase II, multi-center, open-label study of the safety and efficacy of high-dose pulse administration DN-101 (calcitriol) in patients with myelodysplastic syndrome. Contact: Liz Kuczkowski. Phone: 216-445-3795.

Fred Hutchinson Cancer Research Center. FRCRC #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. #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. 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. FHCRC #117. Transplantation of patients with aplastic anemia from related donors following conditioning with antithymocyte globulin (ATG) and cytoxan (CY). Patients up to 55 years of age. Contact: R. Storb, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center. FHCRC #800. Transplantation from unrelated donors for patients with aplastic anemia who have failed immunosuppressive therapy. Conditioning involves ATG, CY and 200 cGy of total body irradiation. Patients up to 55 years of age. Contact: H.J. Deeg, MD. Phone 206-288-1024.

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

Fred Hutchinson Cancer Research Center. 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.

MD Anderson Cancer Center. DM02-089. An open-label, Phase II (Proof of Concept) trial of PKC412 monotherapy in patients with acute myeloid leukemia (AML) and patients with high risk myelodysplastic syndromes (MDS). Contact: Elihu H. Estey, MD. Phone: 713-792-7544.

MD Anderson Cancer Center. DM02-122. Phase II study of arsenic trioxide in the treatment of myelodysplastic syndromes. Contact: Miloslav Beran, MD, PhD. Phone: 713-792-2248.

MD Anderson Cancer Center. DM01-549. Phase III randomized, open label trial of decitabine (5-AZA-2'Deoxycytidine) versus supportive care in adults with advanced-stage myelodysplastic syndrome. Contact: Jean-Pierre Issa, MD. Phone: 713-745-2260.

MD Anderson Cancer Center. 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. ID01-591. DCTER chemotherapy in patients ages 1 through 49 with untreated AML or high-risk myelodysplasia. Contact: Elihu H. Estey, MD. Phone: 713-792-7544.

MD Anderson Cancer Center. DM01-260. A multicenter Phase I/II study of continuous oral administration of SCH 66336 in patients with advanced myelodysplastic syndrome, acute myelogenous leukemia, chronic myelogenous leukemia in blast crisis, acute lymphoblastic leukemia. Contact Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center. ID99-031. Phase II study of intravenous homoharringtonine in chronic myelogenous leukemia (CML). Contact: Jorge Cortes, MD. Pone: 713-794-5783.

MD Anderson Cancer Center. DM01-607. Phase I/IIA study of TLK 199 HCL liposomes for injection in myelodysplastic syndrome. Contact: Stefan Faderl, MD. Phone: 713-745-4613.

MD Anderson Cancer Center. DM03-0096. A Phase I study of triapine and cytarabine in patients with hematologic malignancies. Contact: Francis J. Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center. ID01-152. Safety and efficacy trial of bevacizumab: anti-VEGF humanized monoclonal antibody (NSD 704865) therapy for myelodysplastic syndrome (MDS). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center. DM02-202. A Phase I trial of VNP40101M, a novel alkylating agent, for patients with hematologic malignancies. Contact: Francis J. Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center. DM01-646. A Phase I study of ABT-751 in patients with refractory hematologic malignancies. Contact: Francis J. Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center. ID01-168. A Phase I study of a continuous infusion schedule of (E)-2'-deoxy-2'-(Fluoromethylene) cytidine (tezacitabine, MFdC) in hematologic malignancies. Contact: Stefan Faderl, MD. Phone: 713-745-4613.

MD Anderson Cancer Center. ID02-074. A Phase I/II study of clofarabine in combination with cytarabine (Ara-C) in adult patients in first relapse or first salvage of primary refractory AML or ALL (maximum, two inductin courses); with high-risk MDS; or with CML blast phase as front line therapy or in first salvage. Contact: Stefan Faderl, MD. Phone: 713-745-4613.

MD Anderson Cancer Center. DM02-711. A Phase II, multi-center, open-label study of the safety and efficacy of high-dose pulse administration DN-101 (calcitriol) in patients with myelodysplastic syndrome. Contact: Guillermo Garcia-manero, MD. Phone: 713-745-3428.

MD Anderson Cancer Center. DM02-203. a Phase IA, open-label, three-arm, dose escalation study of PTK787/ZK 222584. Contact: Francis J. Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center. DM97-151. A Phase II study of topotecan (SKF 104864, Hycamptamine), cytarabine (Ara-C) and GM-CSF combination in high-risk refractory anemias. Contact: Miloslav Beran, MD, PhD. Phone: 713-792-2248.

Memorial Sloan-Kettering Cancer Center. 99-057. A 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. 00-116. A 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. 02-004. A randomized, multi-centered, double-blind, placebo-controlled trial assessing safety and efficacy of thalidomide for the treatment of anemia in red blood cell transfusion-dependent patients with MDS. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

Memorial Sloan-Kettering Cancer Center. 01-021. Phase I clinical trial of oral suberoylanilide hydroxamic acid-SAHA (MSK 390) in patients with advanced solid tumors and hematologic malignancies. Contact Mark Heaney, MD, PhD. Phone: 212-639-2275.

Memorial Sloan-Kettering Cancer Center. 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.

Moffit Cancer Center. D-0007. Phase III randomized study of decitabine versus supportive care in patients with advanced myelodysplastic syndrome. Contact: Hussain I. Saba, MD. Phone: 813-972-7582.

Roswell Park Cancer Institute. DS-01-19. Phase III randomized, open-label trial of decitabine versus supportive care in adults with advanced stage MDS. Contact: Dr. James Slack. Phone: 716-845-3544.

Rush Cancer Institute. MDS 2000-08. A pilot study to test the efficacy of gleevec (STI-571) in patients with myelodysplastic syndromes who present with abnormalities of chromosome 12. Contact: Laurie Lisak, PA-C. Phone: 312-563-2538.

Rush Cancer Institute. MDS 801-001. A multi-center, open-label, dose escalation study to determine the safety and preliminary efficacy of the thalidomide analog, CC-1088, in treatment for patients with low-risk myelodysplastic syndromes. Contact: Laurie Lisak, PA-C. Phone: 312-563-2538.

Rush Cancer Institute. MDS 2002-02. A Phase II study to determine the clinical efficacy of Trisenox (arsenic trioxide) as a single agent in myelodysplastic syndromes followed by combination therapy with thalidomide in non-responders. Contact: Laurie Lisak, PA-C. Phone: 312-563-2538.

Rush Cancer Institute. MDS 2002-03. An open-label, Phase II study to evaluate the efficacy and safety of the farnesyl-transferase inhibitor ZARNESTRA (R115777) in subjects with high-risk myelodysplastic syndromes (MDS) who present with myelofibrosis. Contact: Laurie Lisak, PA-C. Phone: 312-563-2538.

Rush Cancer Institute. MDS 2002-04. A pilot study to test the efficacy of a combination of gleevec with thalidomide in patients with idiopathic primary myelofibrosis, myelofibrosis with myeloid metaplasia, and myelodysplastic syndromes who present with myelofibrosis. Contact: Laurie Lisadk, PA-C. Phone: 312-563-2538.

Rush Cancer Institute. MDS 2002-05. A Phase II, multi-center, open-label study of the safety and efficacy of high-dose pulse administration of DN-101 (calcitriol) in patients with myelodysplastic syndrome. Contact: Laurie Lisak, PA-C. Phone: 312-563-2538.

Rush Cancer Institute. MDS 2003-01. A pilot study to determine the clinical efficacy of coenzyme Q10 in patients with myelodysplastic syndromes (MDS). Contact: Laurie Lisak, PA-C. Phone: 312-563-2538.

Shands Hospital at the University of Florida. HM01. A multicenter, open-label, randomized, active controlled Phase I/III clinical trial to evaluate the safety and efficacy of processed unrelated bone marrow in patients with acute or chronic leukemia. Contact: John R. Windgard, MD. Phone: 352-395-0062.

Shands Hospital at the University of Florida. HM03. A multicenter, non-randomized single arm, Phase I clinical trial to evaluate the efficacy and safety of processed bone marrow from mismatched unrelated donors (HLA 5/6) in acute or chronic leukemia patients who are older than 35 years of age. Contact: John R. Windgard, MD. Phone: 352-395-0062.

Stanford University Medical Center. CTEP #2771. Safety and efficacy of bevacizumab: humanized monoclonal anti-VEGF antibody therapy for Myelodysplastic syndrome. Contact: Peter Greenberg, MD or Kathy Dugan, RN. Phone: 650-723-8594.

Stanford University Medical Center. CTEP #38. Phase I/II study of farresy/transferase inhibitor R115777 in patients with myeloproliferative disorders. Contact: Peter Greenberg, MD or Kathy Dugan, RN. Phone: 650-723-8594.

St. Jude Children's Research Hospital. AML02. A 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. HAPSCT. A Phase III randomized trial to evaluate haploidentical stem cell transplantation utilizing purified CD34+ hematopoietic cells for patients with hematologic malignancies: a randomized study comparing positive and negative selection methodologies. Contact: Gregory Hale, MD. Phone: 901-495-3300.

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

University of Arizona Cancer Center. Phase II multicenter study of arsenic trioxide in patients with myelodysplastic syndromes. Contact: Alan List, MD. Phone: 520-626-2340.

University of Arizona Cancer Center. Phase I/II study of continuous oral administration of SCH 66336 in patients with advanced myelodysplastic syndromes. Contact: Alan List, MD. Phone: 520-626-2340.

University of Arizona Cancer Center. Phase II open label study of the efficacy of CC-5013 (Revimid™) treatment for patients with myelodysplastic syndrome. Contact: Alan List, MD. Phone: 520-626-2340.

University of Arizona Cancer Center. Phase II multicenter study of arsenic trioxide in patients with myelodysplastic syndromes (CTI, HSC 01-196). Contact: Alan List, MD. Phone: 520-626-2340.

University of Arizona Cancer Center. A Phase I/II study of continuous oral administration of SCH 66336 in patients with advanced myelodysplastic syndrome, acute myelogenous leukemia, chronic myelogenous leukemia in blast crisis, acute lymphoblastic leukemia (Schering Plough, HSC 01-132) Contact: Alan List, MD. Phone: 520-626-2340.

University of Arizona Cancer Center. A Phase II Open Label Study of the Efficacy OF CC-5013 (Revimid™) Treatment for Patients with MDS (Celgene HSC 01-164) Contact: Alan List, MD. Phone: 520-626-2340.

University of Arizona Cancer Center. A Phase 1A, open-label, 3-arm, dose-escalation study of PTK787/ZK 222584 administered orally on a twice-daily dosing schedule in patients with relapsed or refractory acute myelogenous leukemia (AML) (ARM 1), or patients with secondary and poor prognosis AML, advanced myelodysplastic syndrome (RAEB and RAEBT), and poor prognosis elderly patients with de novo AML (Arm 2), or patients with agnogenic myeloid metaplasia (Arm 3) (Novartis Pharmaceuticals HSC 02-27). Contact Alan List, MD. Phone: 520-626-2340.

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

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

University of Pennsylvania Cancer Center. Phase II trial of arsenic trioxide in patients with MDS—P.I. Contact: Selina Luger, MD. Phone: 215-662-6348.

William Beaumont Hospital. T-MDS-001. A randomized multi-center, double-blind, placebo-controlled trial assessing the safety and efficacy of thalidomide for the treatment of anemia in red blood cell transfusion dependent patients with myelodysplastic syndromes. Contact: Ingrid Tibbits, RN, BSN, OCN.

European Trials

ENGLAND

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Reduced intensity transplants in elderly with MDS and AML using Campath: (CD52) in the conditioning. Contact: Professor G.J. Mufti. Phone: 004-4207-346-3080.

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

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Arsenic trioxide and solium valproate in low-risk MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. FTI inhibitor (Zarnestra) in the treatment of MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. ALG in DR15 and patients with MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Reduced intensity conditioned transplants in Int II and high risk MDS. Contact: Chulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Multi-center study of the role of 5-Azacytidine in high risk MDS (beginning Fall 2003). Contact: Professor Chulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Randomized study of GCSF +Epo versus supportive care in low risk MDS (beginning Fall 2003). Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

GERMANY

University Hospital Frankfort/Main. Antithymocyte Globulin (ATG) and Cyclosporine (CSA) to Treat Patients with Myelodysplastic Syndromes. A randomized trial comparing ATG+CSA with best supportive care Amended Protocol SAKK 33/99. Contact: Wolf-K. Hoffman. Phone: +49-69-6307-5794.

University Hospital Frankfort/Main. Phase II Study with Thalidomide in patients with myelodysplastic syndromes. Contact: Wolf-K. Hoffman. Phone: +49-69-6307-5794.

University Hospital Frankfort/Main. 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: Wolf-K. Hoffman. Phone: +49-69-6307-5794.

University Hospital Frankfort/Main. LAQ824 (inhibitor of histone-deacetylase) in patients with relapsed/refractory AML, advanced CLL, CML in blast crisis or advanced MDS. Contact: Wolf-K. Hofmann. Phone: +49-69-6307-5794.

HUNGARY

Semmelweis University School of Medicine Budapest. Investigation of the multifactorial cause of iron overload in MDS by testing HFE gene for the two known mutations C282Y and H63D and determining copper and eoeruloplasmin level in MDS patients. Contact Judit Varkonyi, MD, PhD. FAX: 361-355-82-51.

ITALY

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

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

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

THE NORDIC COUNTRIES

MAP Study. Diagnostic study on hypoplastic MDS, aplastic anemia and PHN. Contact: Torben Plesner, MD. Phone: 011-46-85-858-0000.

Nordic MDS Group. Maintenance treatment with 5-azacytidine in patients with advanced MDS and MDS-AML, who have obtained CR with intensive chemotherapy. An open perspective Phase II study M\NMDSG02B. Planned to start August 2003. Contact: Eva Hellström-Lindberg, MD, PhD. Phone: 011-46-8-585-800-00.

Nordic MDS Group. Effects of anemia in MDS quality of life, cardiac function and health care costs. An open, non-randomized Phase II study NMDSG03A. Planned to start August 2003. Contact: Herman Nilsson-Ehle.

SCOTLAND

Ninewells Hospital, Dundee/King's College Hospital. Cti 1061. Phase I/II study of arsenic trioxide in patients with myelo-dysplastic syndromes. Contact: David Bowen, MD. Phone: 011-44-1382-86011.

Ninewells Hospital, Dundee/King's College Hospital. Double-blind, randomized, placebo-controlled study on low-dose melphalan for treatment of high-risk myelodysplastic syndromes (MDS) with normal or reduced bone marrow cellularity (PI Claudio Denslinger, Stuttgart, Germany). Contact: David Bowen, MD. Phone: 011-44-1382-86011.

Ninewells Hospital University of Dundee. Identification of markers for early response to the combination of epoietin and G-CSF in the anemia of MDS. Contact: David Bowen, MD. Phone: 011-44-1382-660111.

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.

MDS Patient Registry

PHARMACIA

Pharmacia generously provided an unrestricted grant to help support the Myelodysplastic Syndromes Foundation's Patient Registry. The Foundation gratefully acknowledges this support and looks forward to building the Patient Registry with our Centers of Excellence. The Patient Registry will help further research into the treatment of MDS.

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:

PO Box 353,
36 Front Street
Crosswicks, NJ 08515
or call us at 1-800-MDS-0839.

PHARMION

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

MDS Board of Directors

MDS

About the Foundation

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

Until the Foundation was set up, no formal working group had been devoted to MDS. During the past decade we have conducted seven international symposia—in Austria, England, the United States, Spain, Czech Republic, and Sweden. The Seventh International Symposium will be held May 15-18, 2003 in Paris, France.

One major role of the Foundation is our international information network. This network provides patients with referrals to Centers of Excellence, contact names for available programs, sharing of new research and treatment options, and extension of educational support to both physicians and patients. Ultimately, we hope to provide funding and oversight for international studies in MDS.

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

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*

In Memorium

A memorial fund has been established in the name of

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Ann Shaw
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Ruth Hammond
Holden, MO

Charla Jording
Sedalia, MO

Laura Fetters
Windsor, MO

Carol J. Inman
Littleton, CO

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MDS

Membership Information

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

Membership benefits include quarterly issues of the *MDS News*, a special subscription rate of $105 for *Leukemia Research* (a substantial discount from the current subscription rate of $1,193), and the worldwide Centers of Excellence patient referral service.

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

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

Phone: 1-800-MDS-0839
Fax: 609-298-0590

Outside the US only:
609-298-1035

A memorial fund has been established in the name of

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continued on page 14

In Memorium (continued from page 13)

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Mr. David L. Rigby

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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

PO Box 353, 36 Front Street, Crosswicks, NJ 08515 or call us at 1-800-MDS-0839.

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A memorial fund has been established in the name of

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Mr. Albert J. Strohm

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Alan and Phyllis Horner, *Colorado Springs, CO*

A memorial fund has been established in the name of

Mr. Wilfred (Bud) F. Vallely

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A memorial fund has been established in the name of

Mr. Aaron Wegweiser

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

Beatrice Wegweiser, *Plantation, FL*

A memorial fund has been established in the name of

Dr. Leland (Bud) Weaver

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

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Murrysville, PA

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 referrals to 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 also visit our Web site at *http:www.mds-foundation.org.*

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!!

Suzanne Fleischman Memorial Fund for Patient Advocacy

A fund has been established by the Myelodysplastic Syndromes 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:

Roslyn Raney
Monlo Park, CA

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