From the Guest Editor’s Desk

11th International Symposium on Myelodysplastic Syndromes: An Overview

David T. Bowen, MD
Professor
St. James’s University Hospital
St. James’s Institute of Oncology
Leeds, United Kingdom

Edinburgh, UK: May 18–21, 2011

The May wind and cool temperatures welcomed 1,572 delegates to Edinburgh for the 11th International MDS Symposium. Delegates attended from 58 countries with Spain, Italy and France those countries with the highest delegate numbers. The symposium Chairman had assembled a strong local scientific committee to partner with the Board of Directors of The MDS Foundation in order to prepare an interesting and stimulating scientific programme. Several principles underpinned the programming: short talks, delivered by predominantly younger investigators and, where possible, in the format of a debate. This format was generally successful and seemed to freshen up the symposium and more importantly retain the audience in the hall despite the many attractions that Edinburgh holds for the visitors. Professor Fenaux was particularly impressed by the attendance in the main auditorium throughout Thursday and Friday!

In order to encourage our training staff (scientists, doctors and nurses) we designated a dedicated trainee lounge, preferential positioning of trainee’s posters, and a trainee workshop hosted by Drs. Nimer, Hellstrom-Lindberg, van de Loosdrecht and Steensma. Meet the Expert sessions were provided at lunchtimes and the popularity of morphology workshops run by Drs. Bain, Bennett and Goasguen proved that “morphology was not dead” (a subject debated during the symposium). Sandy Kurtin, Louise Arnold and Erin Demakos organized the parallel sessions for nurses including case studies, clinical trials issues and nurse-led transfusion programmes. The MDS Patient Support UK Group ran a successful patient forum with guest speakers from the faculty.

Drs. Nimer and Bowen welcomed delegates on behalf of the organizing committee and the MDS Foundation. The introductory session on the late afternoon of Wednesday 18 May focused on the patient-physician dynamic. Compassionate physicians (Drs. Sekeres and Steensma) and eloquent patients (Patrick Festy and David Hall) provided insight into this complex and challenging interaction. This session was closed by Iain Milne, whose illustrated review of the history of medicine in Edinburgh was the perfect bridge to the Welcome Reception at the National Galleries.

Instead of the traditional talks about epidemiology and morphology, the opening scientific sessions discussed new diagnostic parameters, prognostic scores and quality of life. Although the current state of the art for
diagnosis remains morphology in most centers, the meeting organizers were keen to court controversy by looking to the future at every opportunity. The biology of MDS was then discussed in detail to reflect the explosion of new data since MDS 2009. In particular, presenters discussed stem cell dysregulation, the bone marrow microenvironment, the 5q- syndrome and immune dysfunction, plus the potential for vaccination therapy in MDS. The plethora of molecular, gene expression and epigenetic abnormalities were then discussed with particular reference to MDS/MPN overlap syndromes such as chronic myelomonocytic leukemia in which >50% patients have one or more identifiable clonal marker.

Plenary sessions continued covering all aspects of therapy for MDS including debates in the controversial areas of iron chelation therapy (Steensma vs. Gattermann), lenalidomide for del(5q) MDS (Fenaux vs. Jadersten), and when and whom to offer stem cell transplantation (Mufti vs. Cutler). Each debate was provocative with no clear 'winners'—reflecting the difficulty that we all have with decision making in these aspects of management where there is no right (or “evidence-based”!) answer. The entertainment highlight of the scientific congress was undoubtedly Drs. Steensma and Gattermann who crafted a Minnesota mountain drama out of an otherwise banal (but important) subject: namely iron chelation. Congratulations to them both; they are clearly in the wrong profession! Drs. List and Guillermo-Garcia rounded off the invited plenary talks with an overview of novel agents in clinical trial for MDS patients; maybe one or more of these will be the next “lenalidomide” or “azacitidine”.

A record 330 abstracts were received — many thanks to the abstract reviewers who had to review and score far more abstracts than had been originally anticipated. From these abstracts, 30 were selected for oral presentation and 275 for poster presentation. The quality of abstracts submitted was very high and this was reflected in the outstanding plenary abstract session to close the congress. The predominance of high quality biological data presented at this session reflects the progress in this field, and two abstracts elucidating the biology of MDS with ring sideroblasts were presented. The first, presented by Dr. Hellstrom-Lindberg (on behalf of Dr. Nikpour), outlined more evidence for the central role of the transporter protein ABCB7 in the pathogenesis of ring sideroblast formation; and the second—and the scientific highlight of MDS 2011—describing the high frequency of mutation in the gene encoding a RNA splice factor complex protein SF3B1 in the same patient group, presented by Dr. Papaemanuil.

A more relaxing element of the preparation was the choice of a social programme, expertly coordinated by Kenes International, contracted as the professional conference organizers for their first MDS international meeting (project managed by Ms. Keren Shurkin). The Welcome Reception at the National Galleries provided tranquility and quiet promenading amongst the fine artwork on display in these interesting public spaces. This could not have been more contrasting with the Gala Dinner in which whisky tasting lubricated the legs and arms for the late evening traditional Scottish ceilidh dancing. Dr. Hellstrom-Lindberg bravely danced through cervical nerve compression, and those that thought they could not dance were (generally) proved wrong and captured on camera for posterity.

In summary I believe that the symposium was a success on a number of levels; the quality of the science presented, the encouragement of younger delegates and faculty, and the general bonhomie that pervaded the 4 days and left all feeling that an interest in MDS was to be continued... in Berlin in 2013.

Finally the organizers are grateful for the generosity of the sponsors and exhibitors with whom the MDS Foundation continues to enjoy a productive and creative collaboration.

### Table 1. Bitesize Highlights

<table>
<thead>
<tr>
<th>Venue</th>
<th>Edinburgh International Conference Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delegates</td>
<td>1,572 from 58 countries</td>
</tr>
<tr>
<td>Abstracts</td>
<td>330, with 30 oral presentations</td>
</tr>
<tr>
<td>Scientific highlight</td>
<td>SF3B1 mutation in MDS with ring sideroblasts: Dr. Papaemanuil</td>
</tr>
<tr>
<td>Entertainment highlight</td>
<td>Iron chelation debate: Drs. Steensma and Gattermann</td>
</tr>
</tbody>
</table>

In summary I believe that the symposium was a success on a number of levels; the quality of the science presented, the encouragement of younger delegates and faculty, and the general bonhomie that pervaded the 4 days and left all feeling that an interest in MDS was to be continued... in Berlin in 2013.

Finally the organizers are grateful for the generosity of the sponsors and exhibitors with whom the MDS Foundation continues to enjoy a productive and creative collaboration.
Highlights from 11th International MDS
The MDS Foundation is a multi-disciplinary, international organization devoted to support, research, treatment, and education for patients, caregivers, physicians, and other health care providers. The organization is based upon the premise that international cooperation will accelerate the process leading to the control and cure of these diseases.

Please join us as a member of the Foundation.

JOIN US AS AN MDS CENTER OF EXCELLENCE

Apply for The Centers of Excellence Program:
Would you like your treatment center to become part of the Foundation’s research network and referral system for MDS patients?
Please call us for more information and an application.

MDS FOUNDATION PUBLICATIONS

The MDS Foundation provides the following information to physicians and patients, free of charge:

- The MDS News
- The MDS Messenger (Free E-News)
- Patient Diary
- What Does My Bone Marrow Do?
- Understanding Myelodysplastic Syndromes: A Patient Handbook*
- Anemia, Blood Transfusions, Iron Overload, & Myelodysplastic Syndromes: A Handbook for Adult MDS Patients*

NEW FROM THE FOUNDATION


*Select MDS Patient Handbooks are available in English and the following languages:
- Arabic
- Czech
- Dutch
- French
- German
- Greek
- Hebrew
- Hungarian
- Italian
- Japanese
- Polish
- Portuguese
- Romanian
- Russian
- Spanish
- Swedish
- Turkish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Polish
- Swedish
- Turkish
- Greek
- Portuguese
- French
- Japanese
- German
- Poli
About the Foundation

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

During the past decade, we have independently solicited funding for eleven international symposia that have been attended by over 7,000 individuals — physicians and patients. These symposia are held biannually and have greatly improved our knowledge of these disorders as we continue to provide physicians worldwide with the most up-to-date information on research in MDS. The 12th International Symposium will be held in Berlin, Germany, May 8–11, 2013.

What Does the Foundation Do?
The Foundation works to maintain an international information network to share new research and new treatment options as rapidly as possible, to provide information and educational support for both physicians and patients, and, ultimately, to provide funding and oversight for international studies of MDS. Currently the Foundation supplies patients, physicians, and other interested parties with information in the form of a quarterly newsletter, the MDS News, and The MDS Messenger, our e-newsletter. The Foundation’s website includes patient and physician information. Our web address is http://www.mds-foundation.org.

The Centers of Excellence Program designates institutions that meet the highest standards for diagnosis, treatment, and patient care. These Centers form the referral base for patients seeking first or second opinions and/or additional treatment options from experts in MDS. The Foundation provides patients with a priority referral to any Center of Excellence. Patient advocacy groups are being formed worldwide, and information is available that assists MDS patients and their loved ones in understanding these diseases and the treatment options that are available.

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

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

How Can We Help You?
Please do not hesitate to contact the Foundation if you have any questions.

MDS Headquarters:
4573 South Broad Street
Suite 150
Yardville, NJ 08620

Within the US: 1-800-MDS-0839
Outside the US: 609-298-1035
Fax: 609-298-0590
www.mds-foundation.org

...a survey indicated a very strong interest in, and a great need for, developing a permanent working group of scientists and patient advocates. Up until that time, no formal working group was devoted to these syndromes. The MDS Foundation was born.

At the Third International MDS meeting, attended by epidemiologists, pediatricians (yes, this does occur in children), pathologists, hematologists, oncologists, and bone marrow transplantation experts, a survey indicated a very strong interest in, and a great need for, developing a permanent working group of scientists and patient advocates. Up until that time, no formal working group was devoted to these syndromes. The MDS Foundation was born.
Meeting Announcements

SAVE THE DATE

The 12th International Symposium on MYELODYSPLASTIC SYNDROMES

May 8-11, 2013 | Berlin, Germany

ADVANCING RESEARCH & PATIENT CARE

Symposium Chairmen:
Arnold Ganser, M.D., Ph.D.
Hanover Medical School, Germany
Wolf-Karsten Hofmann, M.D., Ph.D.
University Hospital Mannheim, Germany

www.kenes.com/mds
Next Generation Approaches for Evaluation and Treatment of MDS

December 9, 2011
Manchester Grand Hyatt
San Diego, California

**AGENDA**

Breakfast will be served from 7 to 7:30 am.

7:30—7:40 am  
**Dr. Stephen Nimer**  
Program Overview and Objectives

7:40—8:15 am  
**Dr. Peter Greenberg**  
Updated Prognostic Assessment of MDS: The Revised IPSS (IPSS-R)

8:15—8:50 am  
**Dr. Alan List**  
Molecular Characterization of MDS Risk and Predisposition

8:50—9:25 am  
**Dr. Jacqueline Boultwood**  
Impaired Ribosome Function and Molecular Biology of the 5q- syndrome

9:25–10:00 am  
**Dr. Ghulam Mufti**  
Combinational Therapy and Use of Newer Agents in MDS

10:00—10:35 am  
**Dr. Juliet Barker**  
Advances in Hematopoietic Stem Cell Transplantation for MDS: Umbilical Cord Blood Transplants and Reduced Intensity Conditioning

10:35–11:00 am  
Questions/Answers/Discussion

**LEARNING OBJECTIVES**

▶ To know the updated methods for evaluating prognosis of MDS patients.
▶ To understand underlying patho-genetic lesions and constitutional predispositions in MDS patients.
▶ To understand the connection between various disorders of ribosomal dysfunction and their implications for disease progression.
▶ To be aware of potentially new uses of combinations of currently available drugs for treating MDS and which novel agents are being evaluated in clinical trials.
▶ To understand the current status of indications for umbilical cord blood and reduced intensity conditioning as approaches for HSCT in MDS patients.

**FACULTY**

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

**Juliet Barker, MBBS (Hons), FRACP**  
Memorial Sloan-Kettering Cancer Center  
New York, New York

**Jacqueline Boultwood, PhD**  
John Radcliffe Hospital, University of Oxford  
Oxford, United Kingdom

**Alan F. List, MD**  
H. Lee Moffitt Cancer Center and Research Institute  
Tampa, Florida

**Ghulam J. Mufti, DM, FRCP, FRCPath**  
King’s College London  
King’s College Hospital  
London, United Kingdom

**Stephen D. Nimer, MD**  
Memorial Sloan-Kettering Cancer Center  
New York, New York

**PRE-REGISTRATION**

Does not guarantee admission—please arrive early.
Spreading the Word Worldwide – Patient and Caregiver Education Forums

International Patient Support Groups – We Need Your Help!

The MDS Foundation has embarked on a very exciting project—Patient Support Groups Worldwide!

Patient Support Groups are an excellent resource in assisting MDS patients and their caregivers. Those groups in existence have been vital to educating public awareness of this disease and promoting and supporting scientific research into the treatment and care of patients with MDS. Unfortunately, only a few such local groups exist, mostly in the US and the UK, and a few European countries. There is a pressing need to establish such groups worldwide.

Patient Support Groups have been vital to educating public awareness of this disease and promoting and supporting scientific research...

The Foundation has devoted selected members of its staff to establish and provide technical assistance to patient support groups outside of the United States, with the goal of continuing this progress into 2012 and beyond.

We have reached out to our International Centers of Excellence to request patient support needs specific to their geographical regions. International patient leaders and all healthcare professionals are also encouraged to forward patient support needs, specific to you and/or your geographical region, to the Foundation at patientliaison@mds-foundation.org or 609-298-1035. We look forward to hearing from you!

Please let us know – we will help!

Established MDS Patient Support Groups

UNITED STATES
- Chicago, Illinois Support Group meets on the fourth Tuesday of the month from 1:30–3:00 pm at Northwest Community Hospital’s Cancer Service department (lower level), 800 W. Central Road, Arlington Heights, Illinois. Contact Kim Jensen at kjensen@nch.org or call 847-618-6914.
- Puget Sound, Washington Support Group meets at the Seattle Cancer Care Alliance Center. Contact Steve Kessler at smartmony@msn.com or call 800-877-0168.
- San Francisco Bay Area Support Group meets on the second Sunday of the month at 2 pm at the Park Blvd. Presbyterian Church, 4101 Park Blvd., Oakland, California. Contact 800-MDS-0839 for more information.
- Stanford Cancer Center MDS Patient & Family Support Group meets the 3rd Monday of the month, 6:30–8:00 pm at the Stanford Cancer Center, 875 Blake Wilbur Dr., Palo Alto, 2nd Floor Conference Room CC2105. Group Leader: Lenn Fechter, RN, BSN 650-725-0744.

CANADA
- Toronto, Ontario Support Group Contact William Pearson at william.pearson@sympatico.ca or call 905-561-6999 for information on upcoming meetings.

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

EUROPE (Countryside Groups)
- France: Association Connaître et Combattre les Myélodysplasies
- United Kingdom: UK MDS Patient Forum
- Czech Republic: Czech Republic MDS Forum

Air Transportation Options for Patients

Angels Donate Frequent Flyer Miles

The need for charitable airline tickets for patients traveling to distant specialized medical evaluation, diagnosis or treatment continues to grow.

During the previous year, programs administered by Mercy Medical Airlift provided almost 10,000 free airline tickets to financially-stressed patients, but many more were required. Unfortunately, resources to assist all were not available.

Help patients in need of distant transportation by donating Frequent Flyer Miles and make a difference in the life of a patient requiring distant specialized treatment. For further information go to http://www.donatefrequentflyermiles.org.

Angel Flight – For Those in Need

Air transportation resources may be available for patients considering travel to one of the participating sites that are part of the NIH Rare Diseases.

Angel Flight at NIH provides air transportation for patients who are in financial need and cannot afford the cost of air travel. The Angel Flight at NIH program is administered by Mercy Medical Airlift.

If you are interested in finding out if Angel Flight meets your air transportation needs, contact Marita Eddy at 301-451-9646 or email meddy@mail.nih.gov or check www.angelflightatnih.org.

Spreading the Word Worldwide – Patient and Caregiver Education Forums

International Patient Support Groups – We Need Your Help!

The MDS Foundation has embarked on a very exciting project—Patient Support Groups Worldwide!

Patient Support Groups are an excellent resource in assisting MDS patients and their caregivers. Those groups in existence have been vital to educating public awareness of this disease and promoting and supporting scientific research into the treatment and care of patients with MDS. Unfortunately, only a few such local groups exist, mostly in the US and the UK, and a few European countries. There is a pressing need to establish such groups worldwide.

Patient Support Groups have been vital to educating public awareness of this disease and promoting and supporting scientific research...

The Foundation has devoted selected members of its staff to establish and provide technical assistance to patient support groups outside of the United States, with the goal of continuing this progress into 2012 and beyond.

We have reached out to our International Centers of Excellence to request patient support needs specific to their geographical regions. International patient leaders and all healthcare professionals are also encouraged to forward patient support needs, specific to you and/or your geographical region, to the Foundation at patientliaison@mds-foundation.org or 609-298-1035. We look forward to hearing from you!

Please let us know – we will help!
MDS Patients Share Their Stories...

SUBMITTED FROM HAMILTON, ONTARIO, CANADA

MDS Foundation
Global Patient Support Groups Initiative

Canadians at the MDS Symposium in Edinburgh, Scotland

William Pearson

As part of the 11th MDS International Symposium on Myelodysplastic Syndromes, there was a one-day session that brought together patients from different countries in the hope of establishing successful MDS patient support groups worldwide.

Participating countries were Belgium, Brazil, Canada, Denmark, Greece, Italy, Japan, the Netherlands, Romania and Switzerland. Attendees from Canada included Dr. Karen Yee, and nurses Cindy Murray and Nancy Pringle from Princess Margaret Hospital in Toronto; and Bill and Lisa Dodd, and William and Janet Pearson representing patients and family members.

Presentations highlighting the functions of support groups were made by Rodney Taylor and Sophie Wintrich representing the MDS UK Patient Support Group, and Patrick Festy from the CCM France Patient Support Group. I was very impressed with the extent of information provided by the MDS UK Support Group website: www.mdspatientsupport.org.uk.

MDS and Quality of Life was discussed — covering the negative and positive impact of MDS. Speakers on this subject were Natalie Singer, Beatson Oncology Centre, Glasgow; Jeff Horn, Aberdeen Royal Infirmary; and Phyllis Paterson, Addenbrooke’s Hospital.

Other topics included:
What Exactly is MDS, Symptoms, and How is it Diagnosed — Dr. Sally Killick, Consultant Haematologist, Royal Bournemouth Hospital.
Current Treatments in MDS, the Scottish Perspective — Dr. Dominic Culligan, Consultant Haematologist, Aberdeen Royal Infirmary.
Understanding Clinical Trials and What is Available — Dr. Mark Drummond, Consultant Haematologist and Honorary Senior Clinical Lecturer, Beatson Oncology Centre.

General Questions and Answers Session — Dr. S. Killick, Dr. D. Culligan, Dr. M. Drummond, Natalie Singer, Jeff Horn and Phyllis Paterson.

These topics were followed by a general discussion from each of the participants. What was most interesting was the common thread of issues and problems — regardless of the country.

The group also discussed the lack of knowledge of MDS in the medical fraternity, and the lack of support groups in many countries. As a qualified first connection regarding MDS, I am personally aware of this. I talk to MDS patients throughout North America, as well as to their caregivers.

We also examined the importance of the MDS Centers of Excellence. They would be a good source to foster the formation of support groups in areas where there are none.

As a bonus we were afforded time to explore Edinburgh and the surrounding areas. Some of the highlights of the tour included the city itself, Edinburgh Castle, and a trip to Loch Ness. Much delight came from the photo I took of the Lock Ness Monster — it has put a smile on many faces.

The whole trip was a great experience on all accounts. For the most part, all issues with MDS are similar throughout the world.
To Live With MDS

Aat van den Bos

Since halfway through the nineties of the past century I have regularly had serious tiredness symptoms. Visiting my family doctor, he used to give me the advice to exercise more, go walking, sporting, and so on, and spend some weeks at home.

In 2001, I was again very tired and almost fainted while we were shopping in the city center. Again, I went to my family doctor. This time he took it seriously. My HB was 11.8. Ferrous drinks didn’t work, and intestinal examination gave no clarity.

Then I was sent to an internist and haematologist. He made the diagnosis in August 2001: a kind of MDS. This gave me a big shock and threatened me. He made it clear that there was no sustainable recovery of this illness. I asked for a second opinion at the Vrije Universiteit (VU University) Hospital in Amsterdam. They confirmed the diagnosis.

I stood under the supervision of my internist and haematologist for 4 years until 2005, but regularly kept in contact with the VU University Hospital. In the meantime, my HB declined slow but steady: 10.5 in 2004.

On my holiday I tested my endurance by mountaineering in Austria. I succeeded in reaching the top—but don’t ask me how!

During this process of illness, I was declared unfit for work. It started with 20%, then 40%, and at least 60%. In 2007 I retired.

When my HB had declined to 9.3, my treatment was taken over by the VU Academic Hospital in Amsterdam. It was a good feeling to know that my treating physician, Dr. A.A. van de Loosdrecht, knew a lot about my disease.

In December 2006, I began EPO-treatment (2 injections a week by myself). My HB raised slowly to 10.1.

After a good two years there was no response anymore. My HB declined again to 9.3 and at least 8.5 (!). You feel very tired all day long and get a very passive behaviour.

At that moment—just in time—a new medicine was made available. I was asked to participate in an experiment with the new medicine: Lenalidomide.

This experiment is still ongoing (for two years now). For the moment, it has had a very positive result for me. My HB has raised above 12.8 (last control: 14.1!).

If this situation remains—and that is the big question—I feel healthy and can live very well with my kind of MDS (RARS). Walking 10 km, light mountaineering, getting upstairs, and so on are no problem for me at the moment.

Perhaps I will be declared recovered from MDS. Who knows?

Aat van den Bos, MDS Patient

The MDSF Launches Re-Designed Website

We have launched a new and improved website featuring major enhancements to our popular website. The new homepage has been simplified to showcase featured content and breaking news. We updated our design adding features to make information easier to read and find, and organized information everything under key headings to help you quickly locate specific topics. You’ll find the latest news about our support services and free educational materials to help you, your loved ones or your patients better cope with MDS.

Get Connected with the MDS Foundation Online!

www.mds-foundation.org

OUR SITE TO SEE!
Cookbooks For a Cause

“Annie’s Sweet Tooth” Raises Money for the MDS Foundation

WHAT:
Cookbook created by Nancy Cosenza Nussbaum in loving memory of her sister, Ann Cosenza Hallberg.

INCLUDES:
Recipes for appetizers & beverages, soups & salads, vegetables & side dishes, entrees, breads & rolls, desserts, cookies & candy, and more.

ALSO:
Cooking glossary, baking and cooking hints, and more.

COST:
$13.00 ($10 plus $3 shipping and handling).

ORDER:
1-800-MDS-0839, or email: AnniesSweetTooth@gmail.com

All revenue from the sales of this cookbook will be donated to the MDS Foundation. A special thank you to Tony and Londie Cosenza, Nancy’s parents, for underwriting the cost of publishing this collection of favorite recipes.

Get Involved...

We applaud Nancy and Paul for their valiant efforts. They have both found ways of keeping their loved one’s memories alive by giving to the MDS Foundation and helping patients and families benefit from our educational and patient support programs.

Become a member of our MDSF Development Committee. Whether you are planning a fundraising event or raising contributions in memory of a loved one, or celebrating your loved one’s survival, please consider joining our development committee to brainstorm for help in planning, for creative ideas, for materials and other support by emailing Tracey Iraca: tiraca@mds-foundation.org or call her at 800.637.0839.

The work of the Foundation, including research and education, greatly benefits from donations like Nancy’s and Paul’s. Hopefully new treatments, and eventually a cure for MDS will result from the research efforts that are integral to the Foundation’s work.

4 Years of Golf Tournaments Raise More Than $15,000

A special thank you to Paul Wenzel who held his 4th Annual Golf Tournament in memory of his beloved mother, Karen A. Wenzel, who passed away on June 19th, 2006. This year’s event took place at the Kingston Fairways in Kingston, New Hampshire. The event included a 4-person scramble, BBQ and awards reception. All proceeds raised were donated to the MDS Foundation.

Paul Wenzel: This is my way of trying to help by raising funds...to someday find a cure for MDS and other blood related diseases. Mostly though, it’s to keep the memory of my mother alive. Putting together the golf tournaments each summer gives me the chance to talk about her, and remember all the good times we had together. We have a wonderful group of family and friends that come out each year to support MDS and to remember what a wonderful person my mother was. I love her and miss her everyday!

Melissa Wenzel displays the tournament t-shirt.

Paul and his mother, Helen.


4 Years of Golf Tournaments Raise More Than $15,000

A special thank you to Paul Wenzel who held his 4th Annual Golf Tournament in memory of his beloved mother, Karen A. Wenzel, who passed away on June 19th, 2006. This year’s event took place at the Kingston Fairways in Kingston, New Hampshire. The event included a 4-person scramble, BBQ and awards reception. All proceeds raised were donated to the MDS Foundation.

Paul Wenzel: This is my way of trying to help by raising funds...to someday find a cure for MDS and other blood related diseases. Mostly though, it’s to keep the memory of my mother alive. Putting together the golf tournaments each summer gives me the chance to talk about her, and remember all the good times we had together. We have a wonderful group of family and friends that come out each year to support MDS and to remember what a wonderful person my mother was. I love her and miss her everyday!

Melissa Wenzel displays the tournament t-shirt.

Paul and his mother, Helen.

4 Years of Golf Tournaments Raise More Than $15,000

A special thank you to Paul Wenzel who held his 4th Annual Golf Tournament in memory of his beloved mother, Karen A. Wenzel, who passed away on June 19th, 2006. This year’s event took place at the Kingston Fairways in Kingston, New Hampshire. The event included a 4-person scramble, BBQ and awards reception. All proceeds raised were donated to the MDS Foundation.

Paul Wenzel: This is my way of trying to help by raising funds...to someday find a cure for MDS and other blood related diseases. Mostly though, it’s to keep the memory of my mother alive. Putting together the golf tournaments each summer gives me the chance to talk about her, and remember all the good times we had together. We have a wonderful group of family and friends that come out each year to support MDS and to remember what a wonderful person my mother was. I love her and miss her everyday!

Melissa Wenzel displays the tournament t-shirt.

Paul and his mother, Helen.
Lesson Learned from My Grandfather (Pepa)

“Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.”

– Albert Einstein

Erin Demakos, RN

The above is a quote by Einstein, and it is indeed, excellent advice. Einstein was of course one of the greatest scientists who ever lived, if not the greatest. This is a quote I remember my grandfather saying to me after spending the entire day at the blood bank receiving 2 units of red blood cells. This was something he did every week as his disease advanced. My grandfather, an immigrant from Belfast, Ireland, was an engineer by trade, working at the American Chickle Factory in Astoria, Queens, NY. He worked well into his late 70s. He loved it — and by all accounts, continuing to work well past the age of retirement likely helped extend his life. He was a devout Catholic, very much involved in his church and local community. Every day he would spend his time helping those in need residing in the apartment building where he had lived for over 50 years. I think it would be best if I start from the beginning — even now it feels like yesterday.

Erin Demakos and her Grandfather; 1986

Once upon a time, long ago, in the fall of 1987, I left my position as a Critical Care Nurse in the Surgical Cardiac Intensive Care Unit at Mount Sinai School of Medicine in NY to pursue a new career working as a Hematology/Oncology Clinical Research Nurse in the Department of Neoplastic Diseases at Mount Sinai, under the direction of Drs. James F. Holland and Lewis R. Silverman. Within the same month of beginning my new role, Dr. Silverman diagnosed my grandfather with MDS. At that point, I had been working as the Primary Research Nurse Coordinator on a new national investigational trial of azacitidine (CALGB study #8421) for patients diagnosed with MDS. I was hoping my grandfather could be enrolled in this trial and receive this new treatment. Unfortunately, due to his underlying co-morbidities, he was not eligible. I was in shock, frustrated, and afraid of the unknown outcome and course predicted for my grandfather. Back then we did not have well-established morphologic classification systems for MDS, nor did we understand their implications for clinical management. In addition, we did not have defined NCCN Practice Guidelines for patients with MDS or the IPSS scoring system, and there were no effective treatments. As a hematology nurse I was frustrated that I could not help him.

For over a year and a half my grandfather endured monthly bone marrow aspirations and biopsies. At the end of the procedure he would say, “Thank you. I hope and pray that you can learn from my disease to help others”. His blood and bone marrow cells would be studied in Dr. Silverman’s lab along with other patients diagnosed with MDS. He encouraged us every day to persevere, work hard, and continue to support the efforts in the fight for a cure. Myelodysplastic disease robbed my grandfather of many productive years of life with his family and friends.

My grandfather was a true believer in setting your mind on something and not giving up until it is accomplished. Because of this, he was able to motivate and encourage many others to persevere in the face of adversity or discouragement. This quality was what helped him the most as he neared the end of his own life. Dr. Silverman and I, along with our team, did persevere. Dr. Silverman served as the Principal Investigator and I served as the lead nurse Co-investigator on 2 additional National Cooperative Group trials on Azacitidine (CALGB# 8921 and 9221), which ultimately lead to its approval (Vidaza); the first FDA approved therapy for patients with MDS. It was a team effort! More progress has been made in the past 7 years than in the 30 years since MDS was differentiated from the acute leukemias. As advances in technology and biology have converged, personalized cancer medicine has become possible. Now we can offer hope to not only improve the quality of life, but to also extend the lives for patients with MDS with effective treatments — those that are FDA approved and many new novel drugs being studied in combination.

My grandfather (Pepa), has always been, and will always be a huge part of my life. He taught me to never back away from a challenge. I will continue to work everyday in the field of MDS and contribute to future advances in treatment. And so I say to my grandfather (my loving Pepa) and to the many patients and families suffering with MDS — Thank you for enduring. Thank you for fighting. And thank you for giving me the hope to continue my dedication to improving the outcome and quality of life for patients, families and caregivers impacted with this chronic disease.

Erin P. Demakos, RN, CCRN today: Administrative Director, Myelodysplastic Disease Center and MPD Program, Mount Sinai School of Medicine
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**

**ARIZONA**
Mayo Clinic Hospital
Phoenix, Arizona
Ruben Mesa, MD; James Slack, MD

University of Arizona
Arizona Cancer Center
Tucson, Arizona
Danuka Mahadevan, MD, PhD

**CALIFORNIA**
Cedars-Sinai Medical Center
UCLA School of Medicine
Los Angeles, California
H. Phillip Koehler, MD

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

Stanford University Medical Center
Stanford, California
Peter L. Greenberg, MD

UCLA Center for Health Sciences
Los Angeles, California
Gary J. Schiller, MD

University of Southern California
Keck School of Medicine
Los Angeles, California
Casey L. O’Connell, MD

**FLORIDA**
All Children’s Hospital
St. Petersburg, Florida
Gregory Hale, MD

Mayo Clinic
Jacksonville, Florida
Alvaro Moreno-Aspitia, MD

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

University of South Florida
H. Lee Moffitt Cancer Center
Tampa, Florida
Alan F. List, MD

**GEORGIA**
Emory Winship Cancer Institute
Emory University School of Medicine
Atlanta, Georgia
Amelia Langston, MD

**ILLINOIS**
Loyola University Chicago
Cardinal Bernardin Cancer Center
Maywood, Illinois
Scott E. Smith, MD, PhD

Robert H. Lurie Comprehensive Cancer Center
of Northwestern University
Feinberg School of Medicine
Chicago, Illinois
Olga Frankfurth, MD

Rush University Medical Center
Chicago, Illinois
Stephanie A. Gregory, MD

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

**INDIANA**
Indiana University Medical Center
Indianapolis, Indiana
Larry Crine, MD

**MARYLAND**
The Blood and Marrow Transplant Program at Northside Hospital
Atlanta, Georgia
Asad Bashey, MD

Illinois Institute of Technology
Chicago, Illinois
Robert J. Cerami, MD

Johns Hopkins University
School of Medicine
Baltimore, Maryland
Steven D. Gore, MD

University of Maryland
Greenebaum Cancer Center
Baltimore, Maryland
Maria R. Baer, MD

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

Tufts University School of Medicine
Tufts Medical Center
Boston, Massachusetts
Kellie Sprague, MD

**MICHIGAN**
Barbara Ann Karmanos Cancer Institute
Wayne State University
Detroit, Michigan
Charles A. Schiffer, MD

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

**MINNESOTA**
Mayo Clinic
Rochester, Minnesota
Mark R. Litzow, MD

University of Minnesota
Medical Center
Fairview University of Minnesota
Medical School
Minneapolis, Minnesota
Erica D. Warlick, MD

**MISSOURI**
Washington University
School of Medicine
Siteman Cancer Center
St. Louis, Missouri
John F. DiPersio, MD, PhD

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

**NEW JERSEY**
The Cancer Center of Hackensack
University Medical Center
Hackensack, New Jersey
Stuart Goldberg, MD

**NEW YORK**
Albert Einstein College of Medicine
Cancer Center
Bronx, New York
Amit Verna, MD

Columbia University Medical Center
New York, New York
Azra Raza, MD

Memorial Sloan-Kettering Cancer Center
New York, New York
Stephen D. Nimer, MD

Mount Sinai School of Medicine
New York, New York
Lewis R. Silberman, MD

New York Medical College/Westchester Medical Center
Valhalla, New York
Karen Seiter, MD

North Shore University Hospital
Lake Success, New York
Steven L. Allen, MD

Roswell Park Cancer Center
Buffalo, New York
James E. Thompson, MD

University of Rochester
Cancer Center
Rochester, New York
John M. Bennett, MD

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

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

Wake Forest University School of Medicine
Comprehensive Cancer Center
Winston-Salem, North Carolina
Bayard L. Powell, MD

**OHIO**
Cleveland Clinic Foundation
Tausig Cancer Center
Cleveland, Ohio
Jaroslaw Maciejewski, MD, PhD

The Ohio State Comprehensive Cancer Center
James Cancer Hospital and Solove Research Institute
Columbus, Ohio
Alison R. Walker, MD
Information on Clinical Trials

New Research Protocol Listing

NATIONAL CANCER INSTITUTE TRIALS

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

■ Log on to www.cancer.gov
■ Click on “Search for Clinical Trials”
■ Click on “Type of Cancer” and type in ‘myelodysplastic syndromes’
■ Hit search

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

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

Clinical Research Trial With Rigosertib (ON 01910.Na)

Now Enrolling NCT01241500

We would like to announce a clinical trial study for Myelodysplastic Syndrome (MDS) patients who have relapsed after, become refractory to or intolerant to Vidaza® (azacitidine) or Dacogen® (decitabine) treatment.

The accrual of patients is ongoing for the rigosertib (ON 01910.NA) trial in myelodysplastic syndrome (ONTIME) clinical trial NCT01241500.

The primary purpose of this study is to compare overall survival (OS) in patients receiving rigosertib plus best supportive care (BSC) to OS of patients receiving BSC in a population of patients with MDS with excess blasts (5% to 30% bone marrow blasts) having failed, being intolerant, or relapsing after azacitidine or decitabine treatment.

Rigosertib is an investigational agent being evaluated for MDS, other blood malignancies and solid tumors. Patients in both the rigosertib arm and the control arm will be monitored closely throughout the trial and hospital stays are not required.

In an effort to accelerate the clinical development of rigosertib for myelodysplastic syndromes the MDS Foundation will be assisting the sponsor and would appreciate hearing from you.

If you are a physician or health care provider and would like to refer a patient for enrollment into this clinical trial OR if you are an MDS patient who has failed, become intolerant, or relapsed after Vidaza® (azacitidine) or Dacogen® (decitabine) treatment, please call the ONTIME Trial Help Line at 1-855-609-6564.

Virginia G. Piper Cancer Center
Scottsdale, AZ
PI: Mahesh Seetharama, MD

Desert Hematology Oncology
Rancho Mirage, California
PI: David Young, MD

Stanford Cancer Center
Palo Alto, CA
PI: Peter Greenberg, MD

Aventura Healthcare Associates
Aventura, FL
PI: Enrique Davila, MD

Integrated Community Oncology
Jacksonville, FL
PI: Lisa Reale, MD

Mount Sinai Cancer Centers
Miami Beach, FL
PI: Jose Lutzky, MD

Martin Memorial Cancer Center
Stuart, FL
PI: Guillermo Abesada-Terk, MD

Lake County Oncology and Hematology
Tavares, FL
PI: Maen A. Hussein, MD

University of Chicago Medical Center
Chicago, IL
PI: Lucy Godley, MD

Rush University Medical Center
Chicago, IL
PI: Jamile Shammo, MD

Edward Kaplan MD & Assoc.
Skokie, IL
PI: Marlon Kleinman, MD

Mary Bird Perkins Cancer Center
Baton Rouge, LA
PI: Bryan Bienvenu, MD

Univ. of Maryland Greenbaum Cancer Center
Baltimore, Maryland
PI: Maria Baer, MD

Johns Hopkins Hospital
Baltimore, Maryland
PI: Steven D. Gore, MD

Dana-Farber Cancer Institute
Boston, MA
PI: David Steensma, MD
Online Search Tool for Clinical Trials

TrialCheck

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

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

www.CancerTrialsHelp.org

New Research Protocol Listings

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS and has updated its International Clinical Trials list on our website and for distribution.

Please contact us for a detailed listing featuring new protocols:
Website: www.mds-foundation.org
Email: patientliaison@mds-foundation.org or call 800-MDS-0839 and the current clinical trials will be sent to you.

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

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

Announcing New Clinical Trials

NAME OF INSTITUTION:
Novartis Pharmaceuticals
TRIAL NUMBER: NCT00940602
Title of Trial or Description:
Myelodysplastic Syndromes (MDS) Event Free Survival With Iron Chelation Therapy Study (TELESTO)
A Multi-center, Randomized, Double-blind, Placebo-controlled Clinical Trial of Deferasirox in Patients With Myelodysplastic Syndromes (Low/Int-1 Risk) and Transfusional Iron Overload
Currently Recruiting Participants.
The primary purpose of this study is to prospectively assess the efficacy and safety of iron chelation therapy with deferasirox compared to placebo in patients with myelodysplastic syndromes (low/int-1 risk) and transfusional iron overload.

Contact the Novartis Clinical Trials Hotline at 800-340-6843 or go to www.clinicaltrials.gov for additional information and to view the active sites.

NAME OF INSTITUTION:
Celgene Corporation
TRIAL NUMBER: NCT01029262
Title of Trial or Description:
A Study of Lenalidomide Versus Placebo in Subjects With Transfusion Dependent Anemia in Low Risk Myelodysplastic Syndrome (MDS) Without Del 5Q (MDS-005)
Currently Recruiting Participants.
The primary purpose of this study is to compare the efficacy of Lenalidomide (Revlimid®) versus placebo in achieving red blood cell transfusion independence in the overall study population and in a pre-specified subgroup of patients with an erythroid differentiation gene expression signature predictive of Lenalidomide response.


University of Michigan Cancer Center
Ann Arbor, MI
Pi: Dale Bixby, MD, PhD

Mayo Clinic
Rochester, MN
Pi: Aref Al-Kali, MD

Saint Louis Cancer Center
St. Louis, MO
Pi: Mark J. Fesler, MD

Hackensack University Medical Center
Hackensack, NJ
Pi: Stuart Goldberg, MD

Weill Cornell Medical College
New York, NY
Pi: Gail J. Roboz, MD

Cleveland Clinic
Cleveland, OH
Pi: Mikkael Sekeres, MD

Medical University of South Carolina
Charleston, SC
Pi: Robert K. Stuart, MD

Bon Secours St. Francois Health
Greenville, SC
Pi: Gary Spitzer, MD

University of Texas – MD Anderson Cancer Center
Houston, TX
Pi: Guillermo Garcia-Manero, MD

Cancer Care Centers of South Texas
San Antonio, TX
Pi: Roger Lyons, MD

St. Mary’s Medical Center
Huntington, WV
Pi: Arvinder Bir, MD

University of Michigan Cancer Center
Ann Arbor, MI
Pi: Dale Bixby, MD, PhD

Mayo Clinic
Rochester, MN
Pi: Aref Al-Kali, MD

Saint Louis Cancer Center
St. Louis, MO
Pi: Mark J. Fesler, MD

Hackensack University Medical Center
Hackensack, NJ
Pi: Stuart Goldberg, MD

Weill Cornell Medical College
New York, NY
Pi: Gail J. Roboz, MD

Cleveland Clinic
Cleveland, OH
Pi: Mikkael Sekeres, MD

Medical University of South Carolina
Charleston, SC
Pi: Robert K. Stuart, MD

Bon Secours St. Francois Health
Greenville, SC
Pi: Gary Spitzer, MD

University of Texas – MD Anderson Cancer Center
Houston, TX
Pi: Guillermo Garcia-Manero, MD

Cancer Care Centers of South Texas
San Antonio, TX
Pi: Roger Lyons, MD

St. Mary’s Medical Center
Huntington, WV
Pi: Arvinder Bir, MD
Highlights of Latest Literature in MDS

Suneel D. Mundle, PhD
Anuj Marathe

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

DIAGNOSIS:

A single tertiary treatment center experience in a four year observation period highlighted diagnostic discrepancy between referring sites and the tertiary center in 12% of the total patients seen at tertiary center, with a majority of discrepant diagnosis in higher risk MDS. The data identify a need of confirmatory diagnosis among patients referred to tertiary centers.

TREATMENT:

Growth Factors:

This 10 yr single center observation study evaluated high dose rh-EPO (40000 IU×2 per week) treatment in low/intermediate 1 risk patients demonstrating overall response rates of 75%, 66% and 59% after 8, 16 and 24 wks respectively. Pretreatment transfusion dependence and serum EPO levels had impact on response to treatment. The mean overall survival was estimated to be 74 weeks.


Higher doses of rh-EPO have been shown to elicit higher response rates, but are expensive. In the present 5 yr observation study with 55 well selected low/intermediate-1 risk MDS patients subjected to a weekly dose of 40000 IU, the authors demonstrate significant erythroid response (65.5%) after 3 months of treatment and recommend 40000 IU as a cost saving option.

IMiDs:

RBC-transfusion dependent patients with IPSS low-/intermediate-1-risk MDS and del5q31 were treated with 10 mg/day × 21 days or 5 mg/day×28 days of a 28 day cycle of lenalidomide and compared to the placebo group. Significantly higher rates of transfusion independence ≥26 wks (primary endpoint) were noted with 10 and 5 mg of lenalidomide, 56% and 43%, respectively, as compared to 6% with placebo. RBC-transfusion independence ≥8 wks was associated with significant reduction in risk of death and leukemic transformation.

5. Göhring G et al. Telomere shortening, clonal evolution and disease progression in myelodysplastic syndrome patients with 5q deletion treated with lenalidomide. Leukemia. 2011, Jul 29 [Epub ahead of print].

Fourteen transfusion dependent 5q del low/intermediate 1 risk MDS cases received lenalidomide. Seven patients had disease progression after a median of 29 months. The patients with progression had shortened pretreatment telomere length in general and in del5q clones as compared to normal telomere length in patients without progression. Furthermore, during repeat measurements while on lenalidomide treatment the telomere length appeared to increase, albeit still shorter than normal or as compared to those without progression.


This included poor prognosis previously untreated older AML patients with del 5q, who received induction therapy with 50 mg lenalidomide × 28 days and then 10 mg daily × 21 days in a 28 day cycle until disease progression or intolerable toxicity (N=37 evaluable). Fourteen patients completed induction therapy. Eight continued on maintenance with CR+PR rate of 14% and a median relapse free survival of 5 months. Authors conclude that lenalidomide single agent has only modest activity in these patients.

Demethylating Agents:

A 3 year retrospective study evaluated the impact of the length of treatment with decitabine or azacytidine in high risk MDS. In a total of 137 patients, mean number of treatment cycles were 4 for decitabine and 5 for azacytidine. The number of cycles received correlated with hematologic response in all three lineages.


This study tasted the efficacy of azacitidine, a drug normally used for high-risk MDS patients, in the treatment of AML (Compassionate program). The overall response rate was 32% including CR-12%. The response rate was higher in previously untreated patients as compared to those with a history of exposure to chemotherapy (48% vs. 19% respectively).

Other Agents:

The differences between the safety and efficacy of low (15 mg/m² daily ×5 days) and high dose (30 mg/m² daily ×5 days) IV clofarabine administered to high-risk MDS patients was assessed in fifty-eight patients. Both doses appeared to result in a comparable response rate (Overall Response Rate 41% vs 29% with 15 and 30 mg respectively); however, it was also noted that the lower dose was significantly less toxic.

Two extended dosing schedules of oral drug, ezatiostat (Telintra), a glutathione -S transferase P1-1 inhibitor, were assessed in a randomized ph II study of heavily pretreated low to intermediate-1 risk MDS patients (N=89; 60% transfusion dependent). The two dose schedules evaluated were 1500 mg po bid x 2 wks followed by 1 wk off or 1000 mg po bid ×3 wks followed by 1 wk off. The HI-E response rate was similar on both arms (~22%) including transfusion independence in 11% baseline transfusion dependent patients. An effect of the type of pretreatment was observed with regard to HI-E. Most common adverse events were grade 1/2 gastro-intestinal effects.

PATHOBIOLOGY:


Therapy-related AML (t-AML) demonstrates higher frequency of cytogenetic abnormalities as compared to de novo AML. The common type of t-AML arising 5–7 yrs post alkylating agent therapy with a preceding MDS demonstrates loss of or deletions on chromosomes 5 and/or 7. In contrast, the other type of t-AML that arises shortly after (1–3 yrs) exposure to topoisomerase II inhibitors without an MDS phase often shows gene rearrangements similar to APL. The present review focuses on the latter.


Current prognostic scoring systems do not incorporate somatic mutations to determine the clinical phenotype of MDS patients. This study aimed at identifying somatic mutations that may play a role in MDS and found mutations in 18 genes not reported previously in these disorders. Somatic mutations appear to be common in MDS patients including in patients with normal cytogenetic reports and may be of prognostic value, with mutations in 5 specific genes providing a potentially valuable prognostic signature for overall survival.


Angiogenic factor expression was explored in this study with specific focus on the impact of angiopoietin-1 (Ang-1) gene expression in bone marrow of patients with MDS (N=208). Compared to normal cohort, Ang-1 expression was higher in MDS patients. Also, the elevated level of Ang-1 expression correlated with increased rates of leukemic transformation and significantly shorter overall survival. Thus, Ang-1 expression may serve to enhance clinical prognosis.


Familial heritable heterozygous missense mutation at c.1061C>T (p.Thr354Met) and a 3 bp deletion c.1063_1065delACA (p.Thr355del) mutation in GATA2 transcription factor are reported as likely predisposing factors for early onset of MDS-AML in a total of four families. These changes affected the second zinc finger of the GATA2 protein. Both appear to be dominant loss-of-function mutations affecting GATA2 activity which is critical for hematopoiesis.


A conditional inactivation of ribosomal protein S6 gene in mice leads to manifestation of the features of 5q-syndrome including macrocytic anemia, erythroid hypoplasia and megakaryocytic dysplasia with thrombocytosis. p53 seems to play a critical role in these manifestations.

We would like to thank Suneel Mundle, a member of the MDS Foundation, for his assistance in monitoring these important peer-review publications on MDS. We would also like to thank Anuj Marathe, a student from the Illinois Math and Science Academy (IMSA), who assisted in the preparation of the material.

Charitable Giving

Please think of the MDS Foundation in your holiday giving this year.

For individuals and families affected by MDS, it’s more important than ever to raise funds for the Foundation in 2012. For the past 16 years, the MDS Foundation (MDSF) has provided services to patients, their families, and health-care providers working in the field.

With changes in regulations and restrictions on corporate support, we need your support more than ever this year to continue producing these vital programs.

For the first time, MDSF donors can dedicate the use of their contributions to one of the critical services we provide.

- **PATIENT ADVOCACY**
  - Patient forums, support groups, information requests, referrals

- **RESEARCH**
  - Clinical trial assistance, physician advisory boards, international working groups on cytogenetics, morphology, diagnostics, quality of life

- **HEALTHCARE PROVIDER EDUCATION**
  - International physician and nursing symposia, interactive/web-based continuing education initiatives, abstracts and manuscripts

Kindly use the enclosed donation envelope or go to: www.mds-foundation.org
to donate today.

Thank you for your continued support!
### MDS Educational Resources Order Form

Last Name ___________________________________________ First Name ________________________________
Title __________________________ Affiliation/University __________________________________________________
Address 1 ___________________________________________ Address 2 ______________________________________
City __________________________ State _____________________ Zip/Postal Code ____________________________
Country ________________________ Phone ______________________ E-mail ____________________________
Type of Practice ________________________________________________

Please indicate the quantity you would like to receive of each item. If your order exceeds 2 lbs (.91 kg) then we will contact you to provide a form of payment for the shipping costs. There is no charge for our publications.

<table>
<thead>
<tr>
<th>QTY</th>
<th>PATIENT PUBLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MDS Foundation Newsletter (The MDS News)</td>
</tr>
<tr>
<td></td>
<td>MDS Messenger E-News E-mail Address:</td>
</tr>
<tr>
<td></td>
<td>MDS Foundation Diary for Patients</td>
</tr>
<tr>
<td></td>
<td>Insurance &amp; Reimbursement Resources for MDS Patients: A Guide to Assistance Programs in the United States (New 2011 Revisions!)</td>
</tr>
<tr>
<td></td>
<td>What Does My Bone Marrow Do?</td>
</tr>
<tr>
<td></td>
<td>A Caregiver’s Guide</td>
</tr>
<tr>
<td></td>
<td>It Takes Time to Realize Your Goals</td>
</tr>
<tr>
<td></td>
<td>100 Questions and Answers About Myelodysplastic Syndromes</td>
</tr>
<tr>
<td></td>
<td>Understanding MDS: A Patient Handbook Languages: ❑ English ❑ Arabic ❑ Czech ❑ German ❑ Greek ❑ Hebrew ❑ Hungarian ❑ Italian ❑ Japanese ❑ Polish ❑ Portuguese ❑ Romanian ❑ Russian ❑ Spanish ❑ Turkish</td>
</tr>
<tr>
<td></td>
<td>Anemia, Blood Transfusions, Iron Overload, &amp; Myelodysplastic Syndromes (*English only, translated versions coming soon)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QTY</th>
<th>PROFESSIONAL PUBLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MDS Foundation Newsletter (The MDS News)</td>
</tr>
<tr>
<td></td>
<td>MDS Foundation E-Newsletter (MDS Essentials) E-mail Address:</td>
</tr>
<tr>
<td></td>
<td>Quick Reference Guide — Calculating the IPSS</td>
</tr>
<tr>
<td></td>
<td>Consensus on Iron Overload Reference Card</td>
</tr>
<tr>
<td></td>
<td>Abstracts of the 10th International Symposium on MDS — May 6–9, 2009, Patras, Greece (Leukemia Research)</td>
</tr>
<tr>
<td></td>
<td>Leukemia Research Supplement – Optimizing epigenetic therapies: issues and strategies</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QTY</th>
<th>DONATIONS</th>
<th>VIDEO PROGRAMS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MDS Awareness Pin – $3.99 each Subcutaneous Chemotherapy – Practical guidelines for clinical practice (DVD)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QTY</th>
<th>CME PROGRAMS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Available online only at <a href="http://www.mdsresourcecenter.org">http://www.mdsresourcecenter.org</a></td>
</tr>
<tr>
<td></td>
<td>MDS Awareness Program, Segment 1: The Past &amp; Present in MDS</td>
</tr>
<tr>
<td></td>
<td>MDS Awareness Program, Segment 2: Clinical Presentation, Diagnosis, and Pathology</td>
</tr>
<tr>
<td></td>
<td>MDS Awareness Program, Segment 3: Ineffective Hematopoiesis: Considerations in Diagnosis &amp; Treatment Format: ❑ CD or ❑ Booklet Languages: ❑ English ❑ French ❑ German ❑ Italian ❑ Japanese ❑ Spanish</td>
</tr>
<tr>
<td></td>
<td>MDS Awareness Program, Segment 4: Survival, QoL, and Treatment Options Format: ❑ CD or ❑ Booklet Languages: ❑ English ❑ French ❑ German ❑ Italian ❑ Japanese ❑ Spanish</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QTY</th>
<th>Non-CME CD-ROM PROGRAMS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>EHA 2009: Therapeutic Decision Making in the Treatment of MDS: Challenging the Experts</td>
</tr>
<tr>
<td></td>
<td>ONS 2009: Practical Therapeutic Options &amp; Approaches: Keeping MDS Patients on Track (Case-Based)</td>
</tr>
</tbody>
</table>

PLEASE RETURN THIS FORM TO: The MDS Foundation, Inc, 4573 South Broad Street, Suite 150, Yardville, NJ 08620 United States USA: 1-800-MDS-0839, Outside US: 609-298-1035; Fax: 609-298-0590 Email: jbutchko@mds-foundation.org, www.mds-foundation.org
Contributions to the MDS Foundation

Thank You!

Gifts to the Foundation

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

- Donna Johnson, Lindenhurst, NY
- Carol Holman, San Diego, CA
- Armando R. Ruiz, Huntington Beach, CA
- Sheila Martin, Fairfax, VA
- Nikki Styles, Launceston, Tasmania, Australia
- Joni Hogue, Cibolo, TX
- Michael J. Maher, Summit, NJ
- Robert C. Donoho, Wheaton, IL
- Harold and Florence Ryder, Mechanicsburg, PA
- Margaret L. Fox, Everett, PA
- Victor Pagone, Castro Valley, CA
- Gene Blalock, Orlando, FL
- Herbert I. Vine, East Brunswick, NJ
- Henry M. Blume, Jr., Menlo Park, CA
- Kevin P. Rynn, Marlton, NJ
- Jacobs Ladder Congregation, Maple Glen, PA
- Murray Diamond, Montreal, Quebec, Canada
- Robert M. Wester, Destin, FL
- Aldeane Soot, Lake Oswego, OR
- Melvin Ringel, Baltimore, MD
- Clement and Joan Rancourt, Plantsville, CT
- Delos R. Goddard, Colorado Springs, CO
- Roberto Degl Innocenti, Miami, FL
- Stan Trail, Dekalb, IL
- Barbara B. Young, Waxahackie, TX
- Thomas Pearce, Birmingham, AL
- Craig Scruggs, Jackson, AL
- Lois Smith, Clanton, AL
- William Shulevitz, New York, NY
- Robert Skirboll, Greensboro, NC
- Debra Samuelson, New York, NY
- Margaret B. Reeder, Hobie Sound, FL
- Norma A. Sheridan-Leos, Pearland, TX
- Raymond and Prudence Malles, Warminster, PA
- Len Yool, Los Altos, CA
- Sarah F. Katis Flynn, Madison, AL
- Mohammad Zahir, MD, Roslyn, NY
- Matthew J. Warshauer, Sarasota, FL
- Patricia A. Rhoten, Bridgewater, NJ
- Lucille B. Nase, Centerville, SD
- Matthew J. Keller Jr., Chicago, IL
- Eunice Edgington, Rohnert Park, CA
- Violet Walker, Maryville, TN
- Diana Mick, Signal Mtn, TN
- Alfred and Dorothy Harding, Medford, NJ
- Steve Redpath, Lyndhurst, OH
- Robert Baxter, Worthing, West Sussex, UK
- Marilyn Lasher, Boca Raton, FL
A Special Thank You to

Gabrielle’s Angel Foundation
for Cancer Research

We would like to especially thank Gabrielle’s Angel Foundation for Cancer Research for their generous grant in the amount of $25,000.00 in support of young investigators through the MDS Foundation.

Ronald E. Jerro, Great Falls, VA
Gordon P. Wilson, Richmond, VA
James F. Montgomery, Atlanta, GA
John Crazier, Irvine, CA
Eric Plant, Pompton Plains, NJ
Kathryn Dixon, Atlanta, GA
Justin Vernon, Salem, MA
Leroy & Alvina Schumacher, Columbus, NE
Nora Ephron and Nicholas Pileggi FDN
New York, NY
Judy L. Wagaman, Kulztown, PA
Lawrence M. Sauger
Sterling Heights, MI
John J. Kennedy, Horseheads, NY
Susan J. Ferber, New York, NY
Lorraine B. Gleixner, Greenwood, IN
H. Charles Ryder, Mechanicsburg, PA
Alvin & Rosa Hudgins, University Park, FL
Theresa Johnson, Leonardtown, MD
Estate of Edward Fleischman
Prescott, AZ
Estate of Laura Sullivan
Bloomington, IL

A Living Endowment

Many families are affected by living with the reality of MDS. There is an extraordinary way to contribute to the MDS Foundation and support our mission of working as a resource for patients, families, and healthcare professionals.

A commitment to donate to the Foundation on occasions of loss, birthdays, and anniversary remembrances can be made. Honor your friends or family members on these occasions with a donation, and the MDS Foundation will send an acknowledgment to the recipient, recognizing the occasion.

A Living Endowment donation has been made in honor of:

Susana Esther Ormaechea
This donation was submitted by:
Hanna Pintozzi, Acworth, GA

A Living Endowment donation has been made in honor of:

Victor Nesterovskij
This donation was submitted by:
Ludmilla Lesney, Sunny Isles Beach, FL

A Living Endowment donation has been made in honor of:

Rich Graul
This donation was submitted by:
G2 Inc., Annapolis Junction, MD

A Living Endowment donation has been made in honor of:

William and Patricia Donlin
This donation was submitted by:
Colleen Donlin-Smith, Penfield, NY

A Living Endowment donation has been made in honor of:

Cousin living with MDS
This donation was submitted by:
Kelly Sereno

A Living Endowment donation has been made in honor of:

Cantor Josh Koningsberg
This donation was submitted by:
Robert and Ruth Lesser
Woodbridge, CT

A Living Endowment donation has been made in honor of:

Luca and Stephanie Factor-Lambertini
This donation was submitted by:
Stephanie Factor, New York, NY

A Living Endowment donation has been made in honor of:

Cathern Allen
This donation was submitted by:
Philip S. Allen, Port Huenerne, CA

A Living Endowment donation has been made in honor of:

Don Campbell and Linda Winters
This donation was submitted by:
Marilyn W. Trapp, Columbus, OH

A Living Endowment donation has been made in honor of:

Delph Gustitus’ Mother
This donation was submitted by:
Geoff and Sandy Goldworm, Jupiter, FL

A Living Endowment donation has been made in honor of:

Janet Aarnio
This donation was submitted by:
Chris and Tara Killgore, Gresham, OR

A Living Endowment donation has been made in honor of:

Robert DuFore
This donation was submitted by:
Valerie Dubois, Moss Beach, CA
In Memoriam

A memorial fund has been established in the name of
Ms. Barbara Allen
Donations have been made in Ms. Allen’s memory by:
Pamela Gurstein, Sherman Oakes, CA

A memorial fund has been established in the name of
Mrs. Jean Avola
Donations have been made in Mrs. Avola’s memory by:
Vincent and Ida Lepore, North Salem, NY

A memorial fund has been established in the name of
Mr. Denveil Ball, Sr.
Donations have been made in Mr. Ball’s memory by:
USIT EDW Team, Chantilly, VA

A memorial fund has been established in the name of
Mrs. Barbee Baron
Donations have been made in Mrs. Baron’s memory by:
Barbara Noska
Dr. Spencer Solodor
Flourtown, PA
Abington, PA
Carole Shaffer and Frank Cann
Warrington, PA

A memorial fund has been established in the name of
Ms. Virginia Bast
Donations have been made in Ms. Bast’s memory by:
Stephan Perry, Morro Bay, CA
Annette, Erick, Chris, Brenda, Sergio, Jennifer, Emily, and Tami Dominguez, Escondido, CA

A memorial fund has been established in the name of
Dr. David Becker
Donations have been made in Dr. Becker’s memory by:
Brian H. Miller, D.D.S.
Newton Centre, VA

A memorial fund has been established in the name of
Mr. John I. Benson
Donations have been made in Mr. Benson’s memory by:
Karen Tisch
Crystal Lake, IL
Darryl and Janice Smith
Marblehead, MA
Dennis and Nancy Raeder
Elkhart, WI
Pete Frencl
Crystal Lake, IL
Mr. and Mrs. David A. Berg and Matthew
Bristol, WI
John & Madaline Wallerius
San Diego, CA
Michael & Maureen Pariberg
Crystal Lake, IL

A memorial fund has been established in the name of
Mrs. Tabitha Berkowitz
Donations have been made in Mrs. Barkowitz’ memory by:
Sherry Lee Berkowitz
Fresh Meadows, NY

A memorial fund has been established in the name of
Mr. Walter Binasiewicz
Donations have been made in Mr. Binasiewicz’ memory by:
Alex & Lorraine Karpovitch
Warrington, PA
Tom and Margaret Walls
Warminster, PA
Walter & Theresa Johnson
Schnecksville, PA
Glenn and Diane Kasten, Center Valley, PA

A memorial fund has been established in the name of
Mr. David Biolos
Donations have been made in Mr. Biolos’ memory by:
Kari and Ruth Hess & Family, West Nyack, NY

A memorial fund has been established in the name of
Mr. Phillip Blair
Donations have been made in Mr. Blair’s memory by:
Cargill Texturing Solutions
Wayzata, MN
Chandler, AZ
Josee and Maria
Artaechevarria Center, CO
Paradise Valley, AZ
Steve and Debbie Tidler
Parker, CO
Michael and Tina Sweeney
Rocklin, CA
Donna Chamberlain
Foxfield, CO
Joe and Lee Shirley
Parker, CO
Charles and Denise Bouley
Parker, CO
Golden Baldock,
James & Paula Kellogg
Manicopa, AZ
Lisa Davis, Troy, OH
Tom and Teresa McHenry
Parker, CO
Betty Jo Daugherty
Manicopa, AZ

A memorial fund has been established in the name of
Ms. Amanda Bohannon
Donations have been made in Ms. Bohannon’s memory by:
Chris Bohannon, Princeton, TX

A memorial fund has been established in the name of
Mr. Melvin Brazman
Donations have been made in Mr. Brazman’s memory by:
Sheri, Alan, Brett & Brian Rothstein

A memorial fund has been established in the name of
Ms. Peggy Joyce Shoun Cannon
Donations have been made in Ms. Cannon’s memory by:
Brown Gardemas
Johnson City, TN
Bob and Joni Davis
Johnson City, TN
Joseph and Sarah Morgan
Jonesborough, TN

A memorial fund has been established in the name of
Mr. William Charnow
Donations have been made in Mr. Charnow’s memory by:
Ruth Jakoff & “Kappy” Kaplan, Boynton Beach, FL

A memorial fund has been established in the name of
Mr. Clem Cahall
Donations have been made in Mr. Cahall’s memory by:
Claire-Elizabeth Sloan, Portland, OR

A memorial fund has been established in the name of
Ms. Pauline E. Christensen
Donations have been made in Ms. Christensen’s memory by:
Karen C. Hanson
Hudson, IA
Marius P. Christensen
Cedar Falls, IA

A memorial fund has been established in the name of
Ms. Carolyn Clayton-Pestor
Donations have been made in Ms. Pestor’s memory by:
Donald and Marilyn Meir, Dana Point, CA

A memorial fund has been established in the name of
Mr. Robert Lawrence Clover
Donations have been made in Mr. Clover’s memory by:
Norma W. Brodsky
Alexandria, VA
Kinhoch Yane Family
Elizabeth Godoy
Chantilly, VA
Jeffrey Lacquement
ACE Sunshine Committee
Springfield, VA

A memorial fund has been established in the name of
Mr. Nicholas Cocino
Donations have been made in Mr. Cocino’s memory by:
Maria Morales-Masinsin, Jersey City, NJ

A memorial fund has been established in the name of
Ms. Mary Costlang
Donations have been made in Ms. Costlang’s memory by:
Haley & Aldrich, Inc., Manchester, NH

A memorial fund has been established in the name of
Mr. Gilbert Cresov
Donations have been made in Mr. Cresov’s memory by:
Janet Chorkasley, Rochester, NY

A memorial fund has been established in the name of
Ms. Irene Cristiano
Donations have been made in Ms. Cristiano’s memory by:
Charles Foster, Parkin, NJ

A memorial fund has been established in the name of
Ms. Dorothy Deckard
Donations have been made in Ms. Deckard’s memory by:
Philip and Bonnie Sanders
Jerrold and Anna Postle
King Mountain, NC
Dublin, OH
Jo Collins, Williamsburg, MI

A memorial fund has been established in the name of
Mr. Alessandro degl’Innocenti
Donations have been made in Mr. degl’Innocenti’s memory by:
Roberto degl’Innocenti, Miami, FL

A memorial fund has been established in the name of
Mr. Bobby J. Dover
Donations have been made in Mr. Dover’s memory by:
Marys Johnson
Bettendorf, IA
Dean and Joey Arney
Bettendorf, IA
Jack and Nancy French
Bettendorf, IA
Doris Melchert
Bettendorf, IA
A memorial fund has been established in the name of Mr. Edward Fleischman

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

Fay J. Vianetick, Pittsburgh, PA

A memorial fund has been established in the name of Mr. William M. Flynn

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

Sarah F. Katis Flynn, Madison, AL

A memorial fund has been established in the name of Mr. Andreas Fokas

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

Ekaterini Fokas, Astoria, NY

A memorial fund has been established in the name of Mr. David Green

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

Gilda Weber

Virginia Beach, VA

From Friends

Monroe Township, NJ

Stanley Boccoff

Boynton Beach, FL

Howard and Gail Lipschultz

Lincolnshire, IL

Robert and Digna Pimentel

Bettendorf, IA

Gene and Ruth Ruttenmaier

Davenport, IA

Pat and Cathleen Harris

Egan, MN

Jerry and Mary Jo Gorthard

Medina, OH

Miko and Pam McCarthy

East Dubuque, IL

Jim and Pat Theisen

Dubuque, IA

Doug Gothard

Long Grove, IL

Steve and Laurie Gothard

Daytona Beach, FL

Marge Gothard

Bellevue, WA

Brent Rathe and Linda Hanson

Mapaveta, CA

Mark and Sue McCuskey

Bettendorf, IA

Ellen Jorgensen

Davenport, IA

Rosa Fetter

Moline, IL

East Elementary Social Committee

Littleton, CO

Bob and Kay Basham

Bettendorf, IA

Costas & Yvonne Constantinou

Davenport, IA

A memorial fund has been established in the name of Mr. Edward Hrenak

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

Phyllis, Rocky and Brandon Rodriguez,

Fort Lauderdale, FL

A memorial fund has been established in the name of Mr. Karsten Joehnk

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

Charlie and Cathy Skala, Boulder, CO

A memorial fund has been established in the name of Mr. Eric Johnson

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

Joe and Tori McLeod, Buddha, OH

A memorial fund has been established in the name of Mr. Ernest T. Kazensky

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

Mr. & Mrs. Adams

Lakeland, FL

Jimmy Chapman

Vickburg, MI

Jerry and Arlene Clawsen

Lake Wales, FL

Fred and Bobbi Sadler

Lake Wales, FL

Gilbert and Gwen Childers

Lake Wales, FL

A memorial fund has been established in the name of Mrs. Judith N. Kennedy

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

Barry, Diane, Collin, Holly, Maddox & Addison Packer

Dallas, TX

A memorial fund has been established in the name of Mr. Arnold Kroll

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

Ron and Linda Dunn

Albany, NY

James & Harriet Jo Lineberger

New Canaan, CT

Rick, Patty, Brandon, Kevin and Bryan Alexander

David and Rory Jones, New Canaan, CT

A memorial fund has been established in the name of Mrs. Margaret Elizabeth Krock

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

Jeremy L. Krock, DO, FAOCA, Peoria, IL

A memorial fund has been established in the name of Mr. Roy Samuel Kussner

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

Allen Starrett

Charlotte, NC

Phillip, Rocky and Brandon Rodriguez, Fort Lauderdale, FL
A memorial fund has been established in the name of Mrs. Susan Lachut
Donations have been made in Mrs. Lachut’s memory by:
Greg and Stefanie Woods, Cicero, NY

A memorial fund has been established in the name of Ms. Joan C. Lawlor
Donations have been made in Ms. Lawlor’s memory by:
Ernie and Diana Breitung, Jacksonville, FL.

A memorial fund has been established in the name of Mr. James Lawrence
Donations have been made in Mr. Lawrence’s memory by:
Staff and Friends at Behavioral Health Partners, Frederick, MD

A memorial fund has been established in the name of Mr. Theodore Joseph Lehmann
Donations have been made in Mr. Lehmann’s memory by:
Tom and Carol Siebe, Petaluma, CA
Phil Garzoli, Petaluma, CA
Team Ghiotti, Inc., Petaluma, CA
Mickey and Elaine Rebecchi, Watsonville, CA
Joanne Thomas, Santa Rosa, CA
Elmo and Dina Maggiora, Sausalito, CA
Bill Allen, Petaluma, CA
The Tingstrom Family, Petaluma, CA
Ross and Laurie Leask, Petaluma, CA
William and Patricia Wright, Novato, CA
Christine Lehmann, Coon Rapids, MN
Martha Olson, Sonora, CA

A memorial fund has been established in the name of Mr. Ralph Lewis
Donations have been made in Mr. Lewis’ memory by:
Christie Comunale, Islip, NY
Ron and Peg Larocca, Fallbrook, CA
Bruce & Maureen Mathews, Huntington, NY
Elizabeth Romero, Bay Shore, NY
Ron and Rose Ann Miners, Northport, NY
The Cappelli Family, Garden City, NY
Richard A. Marchant, Smithtown, NY

A memorial fund has been established in the name of Dr. Grace Yu-Sheng Lo
Donations have been made in Dr. Lo’s memory by:
Norman and Ann Craig, Oberlin, OH
MacPhail Properties, Inc., San Rafael, CA
Lorni Crispin, Lincoln, CA
CSW/Sluder-Streath Engineering Group, Inc., Novato, CA
Mike and Jeanne Williams, Lafayette, CA
Jim and Anne Schroeder, Petaluma, CA
Benita Morris, Fresno, CA
Eckhoff Accountancy Corp., San Rafael, CA
Bette Quaresma, Petaluma, CA
Lois G. Skarsten, Petaluma, CA
Dan and Casey Areana, Petaluma, CA

A memorial fund has been established in the name of Mrs. Gretchen P. Ludmay
Donations have been made in Mrs. Ludmay’s memory by:
Carol L. Schroeder & Family, Riverside, CA

A memorial fund has been established in the name of Mr. James Mason
Donations have been made in Mr. Mason’s memory by:
Knights of Columbus, Newbury Park, CA

A memorial fund has been established in the name of Mr. Ben Rudd Medford, Jr.
Donations have been made in Mr. Medford’s memory by:
Paul and Ann Fisher, Corpus Christi, TX

A memorial fund has been established in the name of Mr. Frank Milewski
Donations have been made in Mr. Milewski’s memory by:
Geraldine Sullivan-Keck, Setauket, NY

A memorial fund has been established in the name of Mr. Michael Miller
Donations have been made in Mr. Miller’s memory by:
Neonatal Practitioners, Charlotte, NC

A memorial fund has been established in the name of Mr. Jeu S. Ming
Donations have been made in Mr. Ming’s memory by:
Lorraine Hayleck, Dayton, MD
Julie Ann Lee, Menlo Park, CA

A memorial fund has been established in the name of Mr. George Mitchell
Donations have been made in Mr. Mitchell’s memory by:
Jo Vanderbeek, Clifton, NJ
Richard and Nellie Samse, Mahwah, NJ

A memorial fund has been established in the name of Ms. Louise Moffett
Donations have been made in Ms. Moffett’s memory by:
ODAR Employees, Knoxville, TN
Kevin Roswell, Fairview, TN

A memorial fund has been established in the name of Mr. Ken Monnens, Sr.
Donations have been made in Mr. Monnens’ memory by:
Edward & Camilla Magnoli, Montpelier, CA
Leslie Piper, San Rafael, CA

A memorial fund has been established in the name of Mr. Irwin Rusty Munter
Donations have been made in Mr. Munter’s memory by:
Lou and Corrine Blonsen, West Palm Beach, FL
Barbara Plumser, Delray Beach, FL

A memorial fund has been established in the name of Mr. Henry S. Mura
Donations have been made in Mr. Mura’s memory by:
Philip and Sara Kinzer, McCormick, SC
Shirley Giroir, Roseland Sloan, & Joy Dupe, Morgan City, LA
Richard and Karen Torrey, McCormick, SC
William and Kathryn Essex, McCormick, SC

A memorial fund has been established in the name of Mr. Albert Nase
Donations have been made in Mr. Albert Nase’s memory by:
Lucille B. Nase, Centerville, SD

A memorial fund has been established in the name of Ms. Elaine J. Noel
Donations have been made in Ms. Noel’s memory by:
C.M. Monti, Ocala, FL

A memorial fund has been established in the name of Mrs. Arlene O’Donnell
Donations have been made in Mrs. O’Donnell’s memory by:
James J. O’Donnell, III, Ocean City, NJ

A memorial fund has been established in the name of Ms. Rose Palitto
Donations have been made in Ms. Palitto’s memory by:
Angelo and Rose Staikos, Hazlet, NJ

A memorial fund has been established in the name of Mr. John Pappas
Donations have been made in Mr. Pappas’ memory by:
Gary and Ann Norlander, Dunedin, FL
Michael Emmons, Sarasota, FL
Tom and Sue Finn, Chicopeee, MA

A memorial fund has been established in the name of Mr. Nelson B. Piper, Jr.
Donations have been made in Mr. Piper’s memory by:
Gary and Ann Norlander, Dunedin, FL
Karen Magenheimer, Palm Harbor, FL

A memorial fund has been established in the name of Mr. Gene A. Rader
Donations have been made in Mr. Rader’s memory by:
Frederick and Joyce Kirlin, Shillington, PA
Robert W. Borrel, Wyomissing, PA
Beverly A. Graeff, Shillington, PA
Patricia A. Owens, West Lawn, PA
Sheryl Baver, Fleetwood, PA
Dennis Trupe, Reading, PA
John Horoshock, Reading, PA
Barbara A. Clark and David H. Melche, Reading, PA

A memorial fund has been established in the name of Mr. Lakshminarayan Ramaswamy
Donations have been made in Mr. Ramaswamy’s memory by:
Shilpa Ramaswamy, Naperville, IL
A memorial fund has been established in the name of
Mr. Mark J. Roder
Donations have been made in Mr. Roder’s memory by:
Richard and Vera Volkwein
Lakewilde, PA
Nora Koch, Cherry Hill, NJ
Terry and Kathy Smith-Jones
Robbins Beach
The Jameson Family, Media, PA
Elizabeth Cornetore
Wallington, PA
Dennis and Marilyn Czekaj
Holland, PA
Erica Spence-Urreata
Yardley, PA
Marina Roden, Astoria, OR
Scott and Marta Mcgovern
Martson, NJ
Aileen Roden, Washington, DC
Sidhbari Roden-Cox, Parker, CO
Alen & Susan Rosenbaum
Delran, NJ
Thomas Roder, Morrisville, PA
Robert & Loretta Wonderlin
Delran, NJ

A memorial fund has been established in the name of
Mr. Willie Roland
Donations have been made in Mr. Roland’s memory by:
Livingston Lions Club, Top Club 62–Yosemite Regional 63
Livingston, CA

A memorial fund has been established in the name of
Mr. Ralph H. Ross
Donations have been made in Mr. Ross’ memory by:
Sonja M. Lampea, Superior, WI

A memorial fund has been established in the name of
Mr. Anthony Rubino
Donations have been made in Mr. Rubino’s memory by:
Laura Scott, Harrington Park, NJ

A memorial fund has been established in the name of
Mr. Breck Ryker
Donations have been made in Mr. Ryker’s memory by:
Ronald Davenport
McLoud, OK
Tammy Mitchell
Forth Worth, TX

A memorial fund has been established in the name of
Mr. Robert Santhys
Donations have been made in Mr. Santhys’ memory by:
David S. Carroll, New York, NY

A memorial fund has been established in the name of
Mr. Carlos M. Santiago
Donations have been made in Mr. Santiago’s memory by:
Rita Santiago, Bronx, NY

A memorial fund has been established in the name of
Mr. Charles Sayer
Donations have been made in Mr. Sayer’s memory by:
Caroline Reilly
New Rochelle, NY
Anna Fusilli, Linden, NJ

A memorial fund has been established in the name of
Mrs. Marlene Schirmer
Donations have been made in Mrs. Schirmer’s memory by:
Dale and Patty Jo O’Neal
Carrollton, KY
Beverly Daily
Colleyville, TX
James & Mary B. Mosgrove
Carrollton, KY
Don and Millie Stehen
Bedford, KY
Danny and Brenda Ader
Carrollton, KY
Sam and Sue Scott
Carrollton, KY

A memorial fund has been established in the name of
Mr. William Schneider
Donations have been made in Mr. Schneider’s memory by:
Gertrude P. Schneider, Wayne, NJ

A memorial fund has been established in the name of
Mr. Edward Schuman
Donations have been made in Mr. Schuman’s memory by:
Kenny and Tracey Romero
Miami, FL
Edward & Dorita Levenstein
Miami, FL
Barbara Goldberg
Fort Lauderdale, FL
Mitchell and Sherry Pantler
Miami, FL

A memorial fund has been established in the name of
Mr. Donald Schultze
Donations have been made in Mr. Schultze’s memory by:
Christine Gassner
Little Neck, NY

A memorial fund has been established in the name of
Mrs. Arlene Schwab
Donations have been made in Mrs. Schwab’s memory by:
Norman Schwab, Los Angeles, CA

A memorial fund has been established in the name of
Ms. Jeanette Scibelli
Donations have been made in Ms. Scibelli’s memory by:
Richard Scibelli
Manalapan, NJ

A memorial fund has been established in the name of
Mr. Paul Seidenberg
Donations have been made in Mr. Seidenberg’s memory by:
Barbara Seidenberg
White Plains, NY

A memorial fund has been established in the name of
Mrs. Reta Joyce Shugart
Donations have been made in Mrs. Shugart’s memory by:
Gail C. Mcglothin
Tyler, TX
Ronnie and Susan Carman
Troup, TX
Lori, Karl and Trinity Vogel
Austin, TX
Rose Cibole, Round Rock, TX
Jerald and Carol Brinkkoefer
Buda, TX

A memorial fund has been established in the name of
Mr. Donald A. Smith
Donations have been made in Mr. Smith’s memory by:
Herdy Waltman, Honesdale, PA

A memorial fund has been established in the name of
Mrs. Sandra K. Smith
Donations have been made in Mrs. Smith’s memory by:
Friends at CNO Corporate Security, Carmel, IN

A memorial fund has been established in the name of
Mrs. Diana Sobanet
Donations have been made in Mrs. Sobanet’s memory by:
Arlene Miles
Denver, CO
David Johns
Salida, CO
Alex and Diana Hammerton
Denver, CO
Petronella Caycedo
Aurora, CO
Bill and Ann Caffrey
Englewood, CO
Nancy McCullin
Parker, CO
Julia Ramsey
Denver, CO
Lee Reichert
Denver, CO
Peter, Regina, Chris
Centennial, CO

A memorial fund has been established in the name of
Mr. Thomas Soudrette
Donations have been made in Mr. Soudrette’s memory by:
Donna & Kevin Dawson
Murfreesboro, TN
Mango Liebert
Cincinnati, OH
Linda Chouteau
Cincinnati, OH

A memorial fund has been established in the name of
Ms. Jane Stewart
Donations have been made in Ms. Stewart’s memory by:
Ruth Cardell
Alameda, CA
Laura Weaver & Family
Portland, OR

A memorial fund has been established in the name of
Ms. Gretchen Street
Donations have been made in Ms. Street’s memory by:
Bhakti Sonali, Fremont, CA

A memorial fund has been established in the name of
Mrs. Helen Tarpening
Donations have been made in Mrs. Tarpening’s memory by:
Amanda Guadino
Detroit, MI
Glenora Schumacher
Chattanooga, TN
Virginia Yeabick
Waterford, MI
Donald M. Horney
Godfrey, IL
Richard & Deborah Wheeler
Waterford, MI
STM Microelectronics, Inc.
Coppell, TX

26
A memorial fund has been established in the name of
Mr. Landon “Butch” Scott Temple, Jr.
Donations have been made in Mr. Temple’s memory by:
Morton Nicholson and
Kristen Strickler
Richmond, VA
Bob and Peggy Ellis, Mechanicsville, VA

A memorial fund has been established in the name of
Donna and Dave Bunton
Donations have been made in Mrs. Toth’s memory by:
Cleveland Heights, OH
Rick and Barbara Wherley

A memorial fund has been established in the name of
Ms. Doris Kjersgaard Thomas
Donations have been made in Mrs. Thomas’ memory by:
Mike and Janet Glidden
Monroe Township, NJ
Jane R. Palmeter
Matawan, NJ
Bruce Levine
North Brunswick, NJ
Frank and Jeanette Ruiz
Rockaway, NJ
Robert B. Counterman
Edison, NJ

A memorial fund has been established in the name of
Mr. Raymond E. Thomas
Donations have been made in Mr. Thomas’ memory by:
Leah Fleming
Walkersville, MD
Grace Folsoom
Laytonville, MD

A memorial fund has been established in the name of
Mr. Robert Edward Thomas
Donations have been made in Mr. Thomas’ memory by:
Bruce Levine
North Brunswick, NJ

A memorial fund has been established in the name of
Ms. Karen Tittel
Donations have been made in Ms. Tittel’s memory by:
Rick and Barbara Wheeler
Cleveland Heights, OH

A memorial fund has been established in the name of
Mrs. Jeanette Toth
Donations have been made in Mrs. Toth’s memory by:
Donna and Dave Bunton
Arlington, VA

A memorial fund has been established in the name of
Ms. Becky Turner
Donations have been made in Ms. Turner’s memory by:
Cassandra Crossing, Locust Valley, NY

A memorial fund has been established in the name of
Mrs. Gayle Lorraine (Timmerman) Vollum
Donations have been made in Mrs. Vollum’s memory by:
Philadelphia Veterans Affairs
Philadelphia, PA
Richard and Sidney Bland
Richmond, VA

A memorial fund has been established in the name of
Mr. Paul Vukelic
Donations have been made in Mr. Vukelic’s memory by:
Mark and Mary Kluch
Ekl Grove Village, IL
Don and Jill Knight
South Elgin, IL
Don and Susan Anderson
Ekl Grove Village, IL
Jeanette Kielh
Patatine, IL
Alan and Cindy Stoeckel and Family
Patatine, IL

A memorial fund has been established in the name of
Mr. Joseph Albert Walker
Donations have been made in Mr. Walker’s memory by:
Brad and Diane Goudine, Ormond Beach, FL

A memorial fund has been established in the name of
Mr. John Wallman
Donations have been made in Mr. Wallman’s memory by:
Bill and Rose Cusack
Massapequa, NY
Robert, Christine and Amela Larose
Merritt Island, FL

A memorial fund has been established in the name of
Ms. Courtenay Wallpe
Donations have been made in Ms. Wallpe’s memory by:
Eileen Silsengleid, Washington, DC

A memorial fund has been established in the name of
Ms. Lila Wanderman
Donations have been made in Ms. Wanderman’s memory by:
Jennifer Hau, Houston, TX

A memorial fund has been established in the name of
Mrs. Karen A. Wenzel
Donations have been made in Mrs. Wenzel’s memory by:
Paul C. Wenzel
South Easton, MA
Paul C. Destefano
North Reading, MA
George R. Costa
Stoneham, MA

A memorial fund has been established in the name of
Ms. Carol L. White
Donations have been made in Ms. White’s memory by:
Elizabeth Bankstahl, Chesterfield, VA

A memorial fund has been established in the name of
Mr. Walter S. Wolodkin
Donations have been made in Mr. Wolodkin’s memory by:
Denise Aparicio
Dallas, TX
Louis A. Egoroff
East Dundee, IL

A memorial fund has been established in the name of
Dr. Marcel Zimetbaum
Donations have been made in Dr. Zimetbaum’s memory by:
Rita Spiro
Bronx, NY
Richard and Susan Alin
Hartsdale, NY
Caryn Dorscoff
Hartsdale, NY
Mark and Joan Josephson
Brookline, MA
Rich Weiss, Fleming, NJ
Meryl Schlussel Mark
Teaneck, NJ
Rina Schunk
Ansbury, NY
Kenny and Bernice Strauss
Youngers, NY
Scott and Shemr Luckow
Ansbury, NY
Judith Wach, Baldwin, NY

A memorial fund has been established in the name of
Dr. Jerry Zuckerman
Donations have been made in Dr. Zuckerman’s memory by:
Denver Public Defenders
Denver, CO

Suzanne Fleischman Memorial Fund
for Patient Advocacy

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

Thank You to Our Pharmaceutical Supporters

We would like to thank our pharmaceutical supporters for their commitment to the Foundation and its work. They have contributed in the form of educational grants, which maintains not only this newsletter but also the development of the MDS homepage on the World Wide Web, the Center of Excellence program, continuing medical education programs, and the dissemination of patient information.
The Foundation’s Board of Directors

John M. Bennett, MD
Professor of Medicine, Emeritus
Laboratory Medicine and Pathology
University of Rochester Medical Center
Rochester, New York, U.S.A.

David T. Bowen, MD
Professor of Hematology
St. James’s University Hospital
St. James’s Institute of Oncology
Leeds, United Kingdom

Mario Cazzola, MD
Professor of Hematology
University of Pavia School of Medicine
Head, Department of Hematology
IRCCS Policlinico S. Matteo
Pavia, Italy

Erin Demakos, RN, CCRN
Administrative Director
Myelodysplastic Disease Center and MPD Program
Mount Sinai School of Medicine
New York, New York, U.S.A.

Theo J.M. de Witte, MD, PhD
Professor of Hematology
University Medical Center Nijmegen
Nijmegen St. Radboud
Nijmegen, The Netherlands

Pierre Fenaux, MD
Professor of Hematology
Hôpital Avicenne
University Paris 13
Bobigny, France

Peter L. Greenberg, MD
Professor of Medicine/Hematology
Stanford University School of Medicine
Stanford, California, U.S.A.

Eva Hellström-Lindberg, MD, PhD
Associate Professor of Hematology
Karolinska Institutet
Institution for Medicine
Huddinge University Hospital
Stockholm, Sweden

Sandra E. Kurtin, RN, MS, AOCN, ANP-C
Hematology/Oncology Nurse Practitioner
Arizona Cancer Center
Clinical Assistant Professor of Nursing
Clinical Assistant Professor of Medicine
University of Arizona
Tucson, Arizona, U.S.A.

Alan F. List, MD
Executive Vice President
Physician-in-Chief, and
The Frank and Carol Morsani Endowed Chair
H. Lee Moffitt Cancer Center & Research Institute
Tampa, Florida, U.S.A.

Silvia M.M. Magalhães, MD, PhD
Professor of Clinical Medicine–Hematology
Federal University of Ceará
Hospital Universitário Walter Cantídio
Ceará, Brazil

Yasushi Miyazaki, MD
Chief, Dept. of Hematology
Nagasaki University Graduate School of Biomedical Sciences
Atomic Bomb Disease Institute
Nagasaki, Japan

John Molle, CPA
JRMM Financial Associates, LLC
Flemington, New Jersey, U.S.A.

Ghulam J. Mufti, DM, FRCP, FRCPath
Professor of Haemat-oncology and Head of Department
Haematological Medicine
King’s College
King’s College Hospital
London, United Kingdom

Charlotte M. Niemeyer, MD
Professor of Pediatrics
University Children’s Hospital
Freiburg, Germany

Stephen D. Nimer, MD
Chairman, The MDS Foundation, Inc.
Vice Chair, Faculty Development
Memorial Sloan-Kettering Cancer Center
New York, New York, U.S.A.

David P. Steensma, MD
Associate Professor
Department of Medicine
Harvard Medical School
Dana-Farber Cancer Institute
Boston, Massachusetts, U.S.A.

Robert J. Weinberg, Esq.
Pepper Hamilton LLP
Philadelphia, Pennsylvania, U.S.A.

Emeritus Members
Terry Hamblin, DM, FRCP, FRCPath
Bournemouth, United Kingdom

Franz Schmalzl, MD
Innsbruck, Austria

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

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

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