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mdsnews
newsletter of the myelodysplastic syndromes foundation

MDS
Join the Journey to Hope

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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 micro-environment, 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.

Table 1. Bitesize Highlights

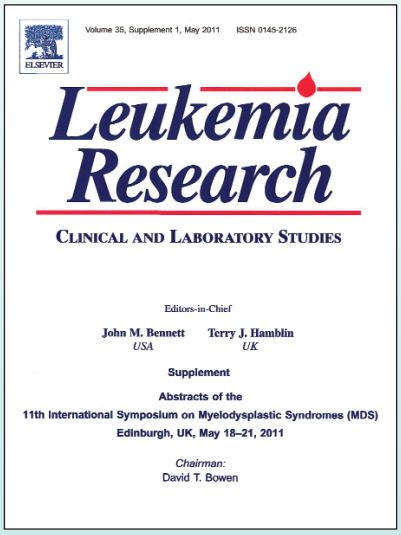
Venue	Edinburgh International Conference Centre
Delegates	1,572 from 58 countries
Abstracts	330, with 30 oral presentations
Scientific highlight	SF3B1 mutation in MDS with ring sideroblasts: Dr. Papaemanuil
Entertainment highlight	Iron chelation debate: Drs. Steensma and Gattermann

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.

11TH INTERNATIONAL ABSTRACTS

The abstracts of the 11th International Symposium on MDS published by Leukemia Research are now available upon request by contacting the MDS Foundation at 1-800-MDS-0839.



Highlights from 11th International MDS

From The Foundation

"helping you give hope..."

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.

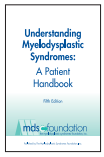
MDS FOUNDATION PUBLICATIONS

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

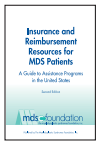
- The MDS News
- The MDS Messenger (Free E-News)
- Patient Diary

- 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*



- Insurance and Reimbursement Resources for MDS Patients



- Planned Giving Program: A Guide to Financial Planning

***Select MDS Patient Handbooks are available in English and the following languages:**

NEW FROM THE FOUNDATION

- A Caregiver's Guide to MDS: What Can You Do to Help?

FOUNDATION INITIATIVES FOR 2012 AND BEYOND...

- **WORLDWIDE PATIENT QUALITY-OF-LIFE FORUMS**
- **WORLDWIDE PATIENT SUPPORT GROUPS**
- **INTERNATIONAL NURSING LEADERSHIP BOARD**

VISIT US ON FACEBOOK AND TWITTER!

facebook twitter

VISIT OUR WEBSITE AND LINK TO OUR EDUCATIONAL RESOURCE CENTER:

www.mds-foundation.org

INTERNATIONAL WORKING GROUPS

These Working Groups are funded through the Foundation and focus on moving disease knowledge forward by developing essential information through innovative research.

- **International Working Group for MDS Morphology**
- **International Working Group for MDS Cytogenetics**
- **International Working Group for Quality of Life in MDS**
- **International Working Group for Prognosis in MDS**

THANK YOU TO OUR SPONSORS FOR THEIR SUPPORT

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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.

...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.

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

SAVE THE DATE

The 12th International Symposium on MYELODYSPLASTIC SYNDROMES

May 8-11, 2013 | Berlin, Germany

ADVANCING RESEARCH & PATIENT CARE

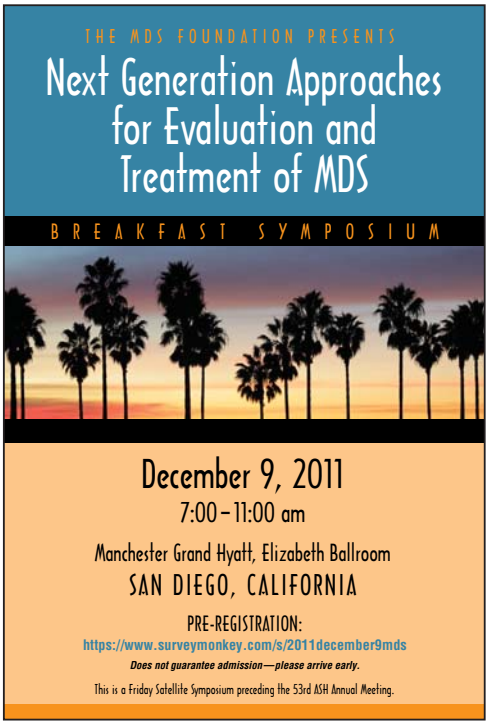
Symposium Chairmen:
Arnold Ganser, M.D., Ph.D.
Hannover Medical School, Germany
Wolf-Karsten Hofmann, M.D., Ph.D.
University Hospital Mannheim, Germany

www.kenes.com/mds

MDS 2013 Symposium Secretariat c/o Kenes International
1-3 Rue de Chantepoulet, PO Box 1726, CH-1211 Geneva 1, Switzerland
Tel: + 41 22 908 0488, Fax: + 41 22 906 9140, E-mail: mds@kenes.com,

For MDS Foundation Contact: US number: 1-800-MDS-0839,
Outside the US: 1-609-298-1035

mds foundation
the myelodysplastic syndromes foundation, inc.



VISIT THE MDS FOUNDATION BOOTH #1517

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 and 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

https://www.surveymonkey.com/s/2011december9mds

Does not guarantee admission—please arrive early.

Patient Forums and Support Groups

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.c*a 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.

Mercy Medical Airlift®
AMERICA'S CHARITABLE MEDICAL TRANSPORTATION SYSTEM

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
National Institutes of Health

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.

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.

The Loch Ness Monster (Nessie)

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.

William Pearson, Dr. Karen Yee, Nurse Nancy Pringle, Janet Pearson, Lisa and Bill Dodd

SUBMITTED FROM NETHERLANDS

To Live With MDS

Aat van den Bos

Since halfway through the nineties of the past century I have regulary 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 home-page 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 every-thing 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!

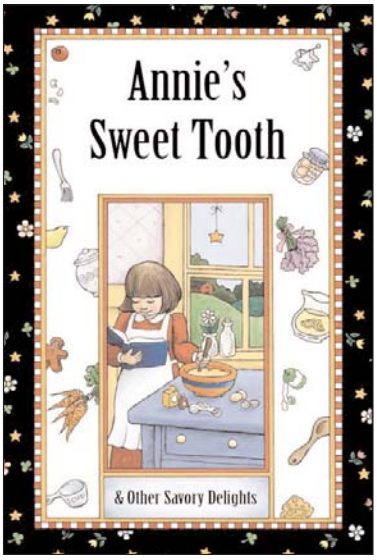
www.mds-foundation.org

OUR SITE TO SEE!

Patient Tributes

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

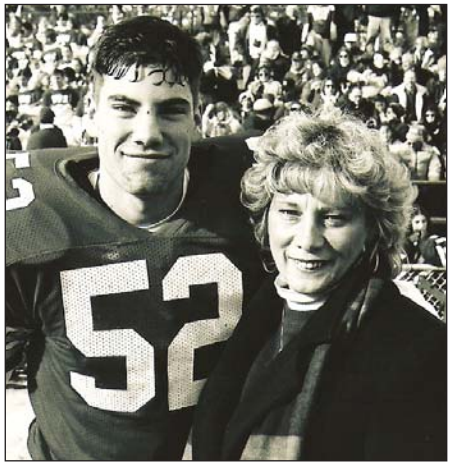
All revenue from the sales of this cookbook will be donated to the MDS Foundation. A special thank you to Tony and Londie Cosenza, Nancy's parents, for underwriting the cost of publishing this collection of favorite recipes.

Ann Cosenza Halberg: 7/1/1959 – 11/21/2009

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!*



Paul and his mother, Helen.

Melissa Wenzel displays the tournament t-shirt.

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.

A Nurse's Story

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.

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

Erin Demakos and her Grandfather; 1986

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

mds centers of excellence

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

- An established university (or equivalent) program
- Recognized morphologic expertise in MDS
- Available cytogenetics and/or molecular genetics
- Ongoing research, including Institutional Review
- Board–approved clinical trials
- Documentation of peer-reviewed publications in the field
- The ability and intention to register patients in the MDS International Registry database

Please contact the Foundation for further information and an application form for your center.

The following centers have qualified as MDS Centers of Excellence:

UNITED STATES

ARIZONA

Mayo Clinic Hospital
Phoenix, Arizona
Ruben Mesa, MD/James Slack, MD

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

CALIFORNIA

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

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

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

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

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

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

INDIANA

Indiana University Medical Center
Indianapolis, Indiana
Larry Cripe, MD

MARYLAND

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

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

MASSACHUSETTS

Dana-Farber Cancer Institute
Boston, Massachusetts
Richard M. Stone, MD
David P. Steensma, 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 Verma, 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. Silverman, MD

New York Medical College/
Westchester Medical Center
Zalmen A. Arlin Cancer 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

Weill 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
Taussig 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

PENNSYLVANIA

The Western Pennsylvania Cancer Institute
Pittsburgh, Pennsylvania
James M. Rossetti, DO

Thomas Jefferson University Kimmel Cancer Center
Philadelphia, Pennsylvania
Emmanuel C. Besa, MD

University of Pennsylvania Cancer Center
Philadelphia, Pennsylvania
Selina Luger, MD

UPMC Cancer Centers University of Pittsburgh Cancer Institute
Pittsburgh, Pennsylvania
Anastasios Raptis, MD

TENNESSEE

Vanderbilt University Medical Center
Nashville, Tennessee
Madan Jagasia, MD
Stephen Strickland, MD

TEXAS

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

Cancer Therapy & Research Center University of Texas Health Science Center
San Antonio, Texas
Swaminathan Padmanabhan, MD

Southwest Regional Cancer Center
Austin, Texas
Richard Helmer, III, MD

University of Texas MD Anderson Cancer Center
Houston, Texas
Guillermo Garcia-Manero, MD
Hagop Kantarjian, MD

WASHINGTON

Fred Hutchinson Cancer Research Center University of Washington Seattle Cancer Care Alliance
Seattle, Washington
Joachim Deeg, MD/Elihu Estey, MD

WASHINGTON, DC

Georgetown University Hospital Lombardi Comprehensive Cancer Center
Washington, D.C.
Catherine Broome, MD

WISCONSIN

Medical College of Wisconsin Bone Marrow Transplant Program
Milwaukee, Wisconsin
Parameswaran Hari, MD

University of Wisconsin Madison Medical School
Madison, Wisconsin
Mark B. Juckett, MD

OUTSIDE THE UNITED STATES

AFRICA

Hôpital Aziza Othmana
Tunis, Tunisia
Balkis Meddeb, MD

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

ARGENTINA

Sanatorio Sagrado del Corazón
Buenos Aires, Argentina
Marcelo Iastrebner, MD

AUSTRALIA

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

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

AUSTRIA

University Hospital of Innsbruck
Innsbruck, Austria
Reinhard Stauder, MD

University of Vienna
Vienna, Austria
Peter Valent, MD

BELGIUM

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

University Hospital Leuven
Leuven, Belgium
Michel Delforge, MD, PhD

BRAZIL

AC Camargo Hospital – Cancer Center
São Paulo, Brazil
Luiz Fernando Lopes, MD, PhD

Hemocentro da UNICAMP
University of Campinas
Campinas, Brazil
Irene Lorand-Metze, MD

Servico de Hematologia do Hospital das Clinicas da Faculdade de Medicina da Universidade de São Paulo
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Universidade Federal de Ceará
Ceará, Brazil
Silvia Maria M. Magalhães, MD, PhD

Universidade Federal de São Paulo
São Paulo, Brazil
Maria de Lourdes Chauffaille, MD, PhD

CANADA

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Toronto, Ontario, Canada
Karen Yee, MD

Toronto Sunnybrook Regional Cancer Centre
Toronto, Ontario, Canada
Richard A. Wells, MD

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

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Institute of Hematology and Blood Diseases Hospital Chinese Academy of Medical Sciences
Tianjin, China
Zhijian Xiao, MD

CROATIA

University Hospital Center Zagreb School of Medicine
Zagreb, Croatia
Boris Labar, MD, PhD
Ranka Serventi-Seiwerth, MD

CZECH REPUBLIC

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

DENMARK

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

Rigshospitalet National University Hospital
Copenhagen, Denmark
Lars Kjeldsen, MD, PhD

University of Århus The University Hospital
Århus, Denmark
Mette Skov Holm, MD, PhD

FRANCE

Centre Henri Becquerel Rouen University School of Medicine
Rouen, France
Aspasia Stamatoullas, MD

Centre Hospitalier Universitaire (CHU) de Angers Service des Maladies du Sang
Angers, France
Norbert Ifrah, MD

Centre Hospitalier Universitaire (CHU) de Grenoble
Grenoble, France
Jean-Yves Cahn, MD

Centre Hospitalier Universitaire (CHU) de Limoges Hôpital Dupuytren
Limoges, France
Dominique Bordessoule, MD

Centre Hospitalier Universitaire (CHU) de Nancy
Nancy, France
Agnés Guerci-Bresler, MD, PhD

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

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

Hôpital Cochin/University Paris V
Paris, France
Francois Dreyfus, MD

Hôpital Saint Louis/University Paris VII
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Hannover, Germany
Arnold Ganser, MD

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

Johann Wolfgang Goethe Universität
Frankfurt Main, Germany
Gesine Bug, MD

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Katharina Götze, MD

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Munich, Germany
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Ulrich Mahlknecht, MD, PhD

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University of Thessaloniki
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Dublin, Ireland
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Tel-Aviv, Israel
Moshe Mittelman, MD

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Tokyo, Japan
Kiyoyuki Ogata, MD, PhD

Saitama International Medical Center
Saitama Medical University
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Seoul, Korea
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Seoul National University College of Medicine
Seoul, Korea
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Nijmegen, The Netherlands
Theo J.M. de Witte, MD, PhD

Vrije Universiteit Medical Center
Amsterdam, The Netherlands
Gert J. Ossenkoppele, MD, PhD

POLAND

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

PORTUGAL

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

ROMANIA

Fundeni Clinical Institute
Bucharest, Romania

SAUDI ARABIA

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

King Khaled University Hospital
King Saud University
Riyadh, Saudi Arabia
Ak Almomen, MD

SINGAPORE

Singapore General Hospital
Singapore
Lay-Cheng Lim, MD

SPAIN

Hospital Universitario de Salamanca
Salamanca, Spain
Consuelo del Cañizo, MD, PhD

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

Hospital Universitario Vall d'Hebron Laboratorio del Citologia-Citogénetica
Barcelona, Spain
Maria Teresa Vallespi-Sole, MD, PhD

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

TAIWAN

National Taiwan University Hospital
Taipei, Taiwan
Hwei-Fang Tien, MD, PhD

THAILAND

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

TURKEY

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

UKRAINE

Research Center for Radiation Medicine
Kiev, Ukraine
Dimitry Bazyka, MD

UNITED KINGDOM

Aberdeen Royal Infirmary
Aberdeen University School of Medicine
Foresterhill, Aberdeen, Scotland
Dominic Culligan, MD

Addenbrooke's Hospital
Cambridge University Hospitals NHS Foundation Trust
Cambridge, United Kingdom
Alan J. Warren, PhD, FRCP, FRCPath

King's College Hospital
University of London
London, United Kingdom
Ghulam J. Mufti, MD

Queen Elizabeth Hospital
University Hospital Birmingham NHS Trust
Birmingham, United Kingdom
Charles Craddock, MD

Radcliffe Hospitals and University of Oxford
Oxford, United Kingdom
Paresh Vyas, MD

Royal Bournemouth Hospital
Bournemouth, United Kingdom
Sally Killick, MD

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

University Hospital of Wales
Cardiff, Wales
Jonathan Kell, 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.

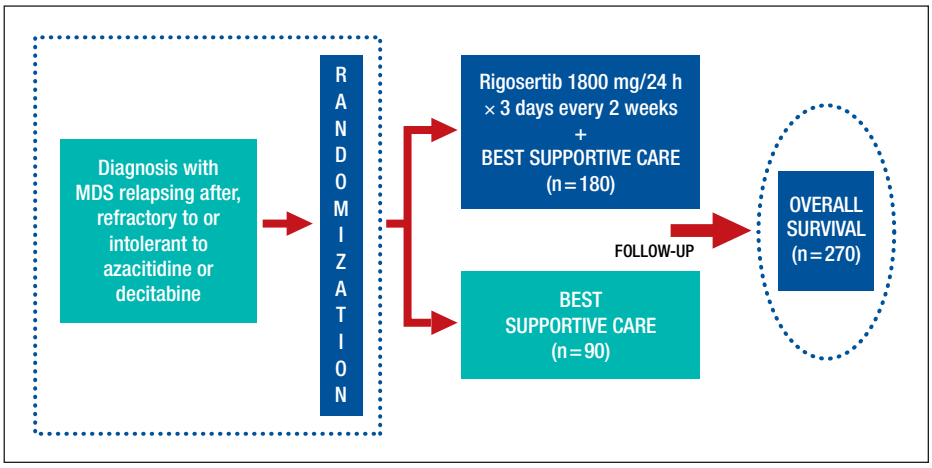
Clinical Research Trial With Rigosertib (ON 01910.Na)

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) **t**rial **i**n **m**yelodysplastic syndrom**e** (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.



Trial Schema

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: Guiellermo 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

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

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.

Online Search Tool for Clinical Trials

TrialCheck® | Clinical trials information and products powered by: Coalition of Cancer Cooperative Groups

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

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.

Access www.clinicaltrials.gov for additional information.

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:

1. Naqvi K et al. Implications of discrepancy in morphological diagnosis of myelodysplastic syndrome between referral and tertiary care centers. *Blood.* 2011, Aug 25. [Epub ahead of print].

   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:

1. Azzará A et al. High dose (40000 IU twice/week) alpha recombinant human erythropoietin as a single agent in low/intermediate risk myelodysplastic syndromes: A retrospective investigation on 133 patients treated in a single institution. *Am J Hematol.* 2011;86(9):762–767.

   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.

2. Balleari E et al. Weekly standard doses of rh-EPO are highly effective for the treatment of anemic patients with low-intermediate 1 risk myelodysplastic syndromes. *Leukemia Research.* 2011, Jul 26 [Epud ahead of print].

   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:

1. Fenaux P et al. A randomized phase 3 study of lenalidomide versus placebo in RBC transfusion-dependent patients with Low-/Intermediate-1-risk myelodysplastic syndromes with del5q. *Blood.* 2011;118(14):3765–76.

   RBC-transfusion dependent patients with IPSS low-/intermediate-1risk 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.

6. Sekeres M et al. A phase II study of lenalidomide monotherapy in patients with deletion 5q acute myeloid leukemia: Southwest Oncology Group Study SO605. *Blood.* 2011;118(3):523–528.

   This study 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.

7. Möllgård L et al. Clinical effect of increasing doses of lenalidomide in high-risk myelodysplastic syndrome and acute myeloid leukemia with chromosome 5 abnormalities. *Haematologica.* 2011, 96(7): 963–971.

   In a prospective phase II multicenter trial, 28 poor prognosis patients (16 AML and 12 int-2/high-risk MDS) were treated with lenalidomide up to a dose of 30 mg daily × 16 wks. Using IWG criteria, the overall response rates were 20% in AML and 36% in MDS. Cytogenetic response was seen in ~25% patients. p53 mutations were associated with a lack of response.

Demethylating Agents:

1. Bordoni RE et al. Hematologic outcomes of myelodysplastic syndromes treatment with hypomethylating agents in community practice. *Clin Lymphoma Myeloma Leuk.* 2011;11(4):350–354.

   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.

2. Maurillo L et al. Azacitidine for the treatment of patients with acute myeloid leukemia: Report of 82 patients enrolled in an Italian compassionate program. *Cancer.* 2011, Jul 14 [Epub ahead print].

   This study tested 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:

1. Faderl S et al. A randomized study of 2 dose levels of intravenous clofarabine in the treatment of patients with higher-risk myelodysplastic syndrome. *Cancer.* 2011, Jul 12 [Epub ahead of print].

   The differences between the safety and efficacy of low (15 mg/m^2 daily × 5 days) and high dose (30 mg/ m^2 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.

2. Raza A et al. A phase 2 randomized multicenter study of 2 extended dosing schedules of oral ezatiostat in low to intermediate-1 risk myelodysplastic syndrome. *Cancer*. 2011, Sep 1 [Epub ahead of print].

   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:

1. Larson RA, Le Beau MM. Prognosis and therapy when acute promyelocytic leukemia and other "good risk" acute myeloid leukemias occur as a therapy-related myeloid neoplasm. *Mediterranean J Hematol and Infectious Diseases*. 2011, Jul 8. [Epub ahead of print].

   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

2. Bejar R et al. Clinical effect of point mutations in myelodysplastic syndromes. *New Eng J Med*. 2011;364(26):2496-2506.

   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.

3. Cheng CL et al. High bone marrow angiopoietin-1 expression is an independent poor prognostic factor for survival in patients with myelodysplastic syndromes. *Br J Cancer*. 2011, Sep 27 [Epub ahead of print].

   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.

4. Hahn CN et al. Heritable GATA2 mutations associated with familial myelodysplastic syndrome and acute myeloid leukemia. *Nature Genetics*. 2011, Sep 2 [Epub ahead of print].

   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.

5. McGowan KA et al. Reduced ribosomal protein gene dosage and p53 activation in low risk myelodysplastic syndrome. *Blood*. 2011 Sep 29.

   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.

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	What Does My Bone Marrow Do?
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	It Takes Time to Realize Your Goals
	100 Questions and Answers About Myelodysplastic Syndromes
	Understanding MDS: A Patient Handbook Languages: ❑ English ❑ Arabic ❑ Czech ❑ German ❑ Greek ❑ Hebrew ❑ Hungarian ❑ Italian ❑ Japanese ❑ Polish ❑ Portuguese ❑ Romanian ❑ Russian ❑ Spanish ❑ Turkish
	Anemia, Blood Transfusions, Iron Overload, & Myelodysplastic Syndromes (*English only, translated versions coming soon)

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	MDS Foundation Newsletter (*The MDS News*)
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	Consensus on Iron Overload Reference Card
	Abstracts of the 10th International Symposium on MDS — May 6–9, 2009, Patras, Greece (*Leukemia Research*)
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Mr. Walter S. Wolodkin

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

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A memorial fund has been established in the name of

Dr. Marcel Zimetbaum

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A memorial fund has been established in the name of

Dr. Jerry Zuckerman

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

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Suzanne Fleischman Memorial Fund for Patient Advocacy

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

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