

MDS NEWS HIGHLIGHTS

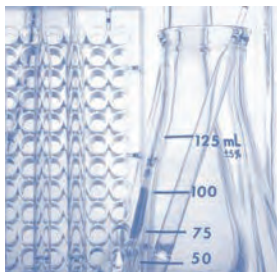
FROM THE GUEST EDITOR'S DESK

■ 12th International Symposium on MDS: An Overview

Presented by *Prof. Dr. med. Wolf-Karsten Hofmann*
and *Prof. Dr. med. Arnold Ganser*



FEATURING MDS CLINICAL TOOLBOX



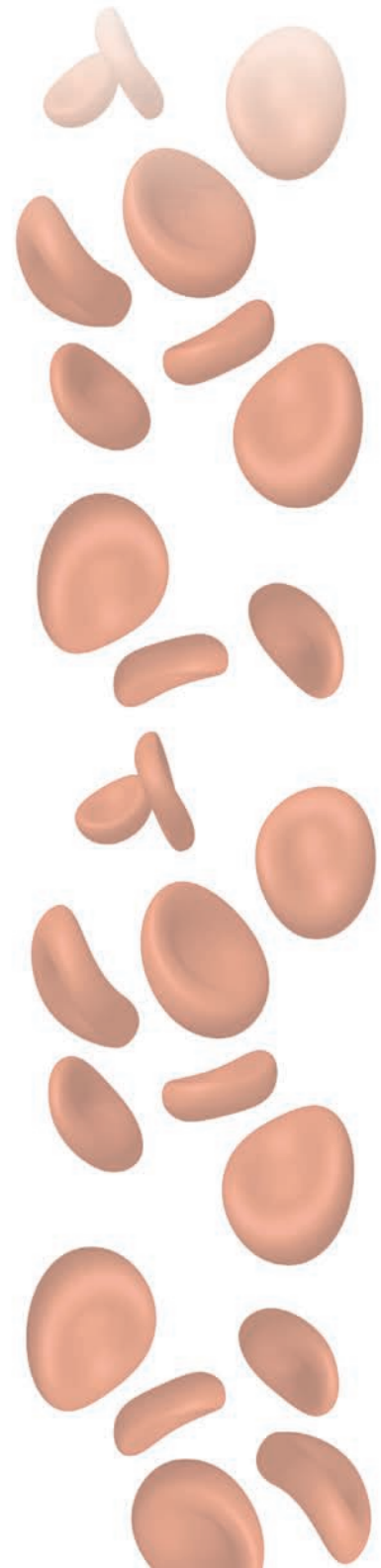
ASH 2013 MDS FOUNDATION BREAKFAST SYMPOSIUM

December 6, 2013 • New Orleans, Louisiana

■ PLAN TO ATTEND!

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12th International Symposium on MDS: An Overview



Wolf-Karsten Hofmann, MD
Florian Nolte, MD
**University Hospital Mannheim,
Germany**

Arnold Ganser, MD
Felicitas Thol, MD
Hannover Medical School, Germany

For the first time the International Symposium on Myelodysplastic Syndromes was held in Germany. In the city of Berlin approximately 1300 attendees from 67 countries joined this 12th International Symposium on MDS. As a novelty the meeting was chaired not by one but two specialists in the field: Arnold Ganser from Hannover Medical School and Wolf-Karsten Hofmann from the University Hospital Mannheim.

As already proven successfully in former meetings, this symposium aimed to allow young investigators enough time to present their work to the scientific community and to use interactive formats whenever possible to create a stimulating atmosphere throughout the meeting. The organizers abandoned parallel sessions from the congress schedule to allow every participant to attend every talk held during the congress.

The first day of the symposium started with two morphology workshops for both beginners and advanced morphologists. Attendees and faculty were deeply involved in discussions on morphological evergreens such as the issue of evaluating the medullary blast count, drawing the line between MDS and MDS/MPN entities as

well as discussions on challenging cases from the daily practice of the attending doctors. The infectious enthusiasm of the faculty, namely Teresa Vallespi (Spain), Gina Zini (Italy), Torsten Haferlach (Germany), Marius MacKenzie (The Netherlands), Masao Tomonaga (Japan), Richard Brunning (United States), Jean Goasguen (France), Ulrich Germing (Germany), and John Bennett (United States) and the vital participation of the attendees made this a perfect start for the entire meeting.

The opening ceremony was very much under the impression of the decease of two MDS patients: In a very affectionate but also humorous way Stephen Nimer (United States) recalled the person, the work, and the impact of Bob Weinberg (†Apr 27th 2013) on the MDS community, while Wolf-Karsten Hofmann recited the optimistic and enjoyable speech of one of his long lasting patients who was supposed to hold an address entitled “Diagnosis of MDS: No reason to stop an active life”. Unfortunately and as an irony of fate, Dieter Mollenhauer died only two weeks prior to being expected to give his speech.

After Dr. Ursula von der Leyen, the German Federal Minister of Labour and Social Affairs who worked as a physician at Hannover Medical School prior to her career in politics, had presented her talk on “The challenge of an aging generation”, the winners of the “Young Investigator Award” of the MDS Foundation amounting to \$50,000 for each awardee were presented by Stephen Nimer and Arnold Ganser. Finally, some attendees of this international congress might have been torn out of their meditateness when the closing lecture on “Rudolf Virchow, Robert Remak and the cellular elements of the blood” was presented by Professor Johanna Bleker from the Humboldt University of Berlin: She challenged the majority of the auditorium with a one hour lecture in German!

As a novelty to this meeting, the plenary sessions not only consisted of classical plenary talks but also one oral presentation on original data submitted to the congress thereby providing a prominent platform to young investigators and researchers. While two years ago in Edinburgh participants of the congress were excited by the brand new data on spliceosome mutations in MDS, the second day in Berlin started with a plenary session dedicated to summarize the data and knowledge on molecular findings acquired so far and their implication in clinical decision making. Timothy Graubert (United States), Seishi Ogawa (Japan), Joop Jansen (The Netherlands), and Benjamin Ebert (United States) elaborated on the “OMEs” in MDS, meaning: the genome, the spliceosome, the epigenome and the impact of “OME alterations” on MDS classification, which provided a felicitous introduction for Elli Papaemmanuil’s (United Kingdom) presentation of original data on clinical implications of gene mutations in MDS.

The second plenary was all about state of the art in MDS. Ulrich Germing highlighted the pros and cons of the current WHO classification and gave a perspective what might be changed in upcoming classifications. Detlef Haase (Germany) and Peter Greenberg (United States) lectured on cytogenetics in MDS and the revision of the IPSS. The session closed with an oral presentation by Ulrich Lehmann (Germany) on one of the hot topics in MDS research: MDS with fibrosis and its overlap with myeloproliferative neoplasms.





The following session chaired by John Bennett was dedicated to diagnostic and therapeutic challenges of MDS and their “MPN relatives” as CMML and RARS-T. To honour one of the great mentors of hematology in general and MDS in particular, John Bennett, Ghulam Mufti (United Kingdom), and David Bowen (United Kingdom) outlined the life and work of Terry Hamblin, who had passed away in 2012, in contemplative, affectionate and entertaining words. Thereafter, David Bowen gave the dedicated “Terry Hamblin Memorial Lecture” on CMML and was honored with the Terry Hamblin medallion.

The day continued with the session “What can MDS specialists learn from...”. This format was newly introduced to the MDS symposium to confront the MDS community with new input from other even very rare diseases with regard to pathophysiology. Chaired by Mario Cazzola (Italy), the plenary speakers Marcin Wlodarski (Germany), Christoph Klein (Germany), and Jaroslaw Maciejewski (United States) highlighted key features of childhood MDS, rare genetic diseases associated with bone marrow failure, and overlap of bone marrow failure and MDS, respectively, and hopefully stimulated the attending researchers to undertake new efforts in order to further elucidate the biology of MDS.

On Friday May 10th, the congress began with two plenaries on treatment of

low and high risk MDS, respectively. Later that day, four researchers were awarded with the “Tito Bastianello Award” for the best abstract. During this session Daniel Nowak (Germany) confronted the audience with data on the establishment of a low risk MDS xenograft mouse model and could show that mesenchymal stem cells promote engraftment of human MDS cells in mice. This work was very actively discussed and could be a real breakthrough in MDS research. Moreover, the crucial role of bone marrow environment in MDS was highlighted by the work presented by Sten Jacobsen (United Kingdom) on the following day in the 6th plenary session of the symposium. This final session was chaired by Steven Gore (United States) who will also be the host of the 13th MDS symposium in Washington, DC in 2015.

Similar to previous meetings a well-attended and even crowded patient forum was held in Berlin as well. Active participation of the attending patients and relatives on the one hand and the informative and entertaining performance of Aristoteles Giagounidis and Uwe Platzbecker (both from Germany) made this forum a great success.

Berlin as one of the most vibrant and dazzling cities in Europe, full of unique spots and locations, surely excited many of the congress participants. One of these spots was the “Wasserwerk” chosen as location for 2013’s gala dinner. The guests enjoyed excellent food, drinks and stimulating conversations in a unique surrounding accompanied with fine live music by Andrej Hermelin and Band.

In conclusion, the meeting in Berlin was an event that had everything: highly interesting scientific data, high quality plenary talks, intensive discussions, contemplative and reflective moments and last but not least moments of (sometimes unintentional) entertainment. As the chairpersons of this symposium we would like to thank the MDS Foundation for their trust in our capability to organize a stimulating meeting of highest scientific quality which also allowed to renew friendships and to make new friends. Furthermore we are thankful to the people from Kenes International who perfectly did the “non-scientific” organization of this meeting. We certainly enjoyed having you all with us in Germany and especially in Berlin.



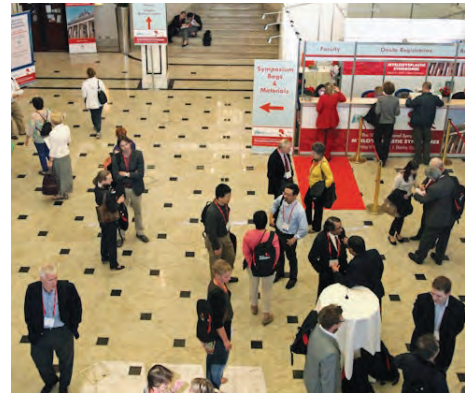
THANK YOU for attending The 12th International Symposium on MDS

Berlin, Germany • May 8–11, 2013

**Educational Webcast and Video Podcast
of all plenary sessions are now available**
<http://webcasting.kenes.com/MDS2013/>.

These expert talks can be accessed from
home/office computers and even on
iPod video, iPhone or iPad.

INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES





INTERNATIONAL PROGNOSTIC SCORING

LATEST NEWS ON THE REVISED INTERNATIONAL PROGNOSTIC SCORING SYSTEM FOR MDS



Developed by the International Working Group for the Prognosis of MDS (IWG-PM) under the aegis of the MDS Foundation, Inc.

Italian Study Supports Use of Revised International Prognostic Scoring System

Results of a recent Italian study show that the Revised International Prognostic Scoring System (IPSS-R) has significantly higher predictive power for leukemia-free and overall survival in myelodysplastic syndromes (MDS) patients than the older International Prognostic Scoring System (IPSS) and the World Health Organization classification-based Prognostic Scoring System (WPSS). The Italian study compared the predicted outcomes of 380 MDS patients as determined by the IPSS-R, IPSS, and WPSS with their actual survival outcomes to determine which prognostic scoring system best predicted survival. The original IPSS was developed in 1997 as a tool to predict survival outcomes among MDS patients based on their chromosomal abnormalities, percentage of immature stem cells (blasts), and number of low blood cell counts. The IPSS-R

uses the same set of parameters as the original IPSS, but includes five rather than three categories of chromosomal abnormalities, as well as new cutoff values for blasts and blood cell counts. For more information, please see the study in the *Journal of Clinical Oncology* (abstract):

<http://jco.ascopubs.org/content/early/2013/06/24/JCO.2012.48.0764.abstract>

NEW ADVANCED IPSS-R CALCULATOR TOOL:

In addition to the 'Basic' IPSS-R calculator tool which incorporates the major clinical variables used to determine prognostic risk category (marrow blasts, cytogenetics, hemoglobin, neutrophil and platelet levels) as well as age, there is now an 'Advanced' IPSS-R calculator tool which also includes 'differentiating features' (performance status, serum ferritin, LDH, beta-2 microglobulin and marrow fibrosis) which are additive to the basic variables. These differentiating features are only applicable for survival (not AML evolution). The URLs to access these calculator tools are:

BASIC: <http://ipss-r.com>

ADVANCED: <http://advanced.ipss-r.com>

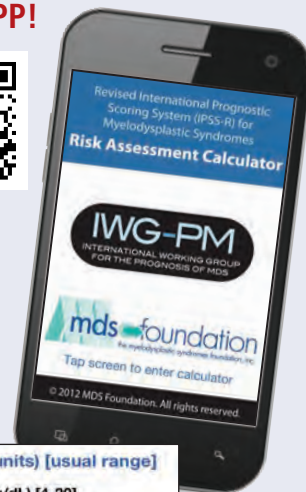
BASIC

<http://www.mds-foundation.org/calculator>

ADVANCED: <http://www.mds-foundation.org/calculator/advanced>

There is also a user-friendly iPhone App for the Basic calculator tool accessed through the Apple Store by searching for 'IPSS-R'. These calculator tools, developed by members of the IWG-PM under the aegis of the MDS Foundation, are derived from the article in *Blood*. 120:2454–2465, 2012.

**TECH IT OUT AND
DOWNLOAD OUR
FREE APP!**



Variables (units) [usual range]
Hemoglobin (g/dL) [4-20] A Possible conversion for Hb values: 10 g/dL=6.2 mmol/L, Bg/dL=5.0 mmol/L
<input type="text"/>
Absolute Neutrophil Count (x10⁹/L) [0-15]
<input type="text"/>
Platelets (x10⁹/L) [0-2000]
<input type="text"/>
Bone Marrow Blasts (percent) [0-30]
<input type="text"/>
Cytogenetic Category ?
Select Category

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Download on the
App Store



May 2013: The MDSF in Berlin

**Bergit Kuhle, MDS-PAT-IG
Germany**



The MDS Forum for patients and their families was held on May 11, 2013 in the Maritim Hotel in Berlin, Germany. The event was part of the Scientific Symposium of the MDS Foundation from May 8–11, 2013.

My Personal Approach

I have two reasons to be part of the MDS community. First I have been an MDS patient for more than seven years now and second I have been connecting with patient organizations and European and International patient committees for quite a while. I am a representative of the German “MDS-Patienten-Interessen-Gemeinschaft (MDS-PAT-IG)”, which can be translated as “Community of Interest for MDS Patients”. The umbrella group behind it is the “Leukämiehilfe Rhein-Main e.V. (LHRM)”, a patient support organization since 1991 which covers rare blood malignancies such as leukemia and lymphomas.

Preparations

In January 2013 we already started with the preparations for the patients’ event. “We” were representatives from various patient support organizations, institutions and countries (Germany, United Kingdom, Spain, USA) conducted by the MDS Foundation ladies in charge. The German “MDS-PAT-IG”, under her umbrella-group “LHRM” was responsible for the promotion

of the patients’ event in Germany. Our joint venture included several program changes, many translations, flyer adjustments, poster discussions, promotion concepts, telephone conferences with minutes and so on, but all in all certainly more than 100 emails between all of us. To have three or four emails per day on the topic was normal for the last two weeks prior to the event. However, the patients’ day showed that it was all worthwhile. By teamwork and collaboration over the months a very professional and successful event for the patients and their families was created. I am thankful to have been on the organization team.

The 11th of May 2013

How many MDS people would finally show up beyond the number of registrants? Would the patients sufficiently interact, so that it would be beneficial for everyone? Would the quality-of-life-session manage to touch the patients on the emotional level so that they would open themselves and talk frankly about their situation? Would they feel comfortable with the atmosphere and the catering? Would the fact that the location was a Four-Star-Hotel be okay? Would we have enough breaks in between for everybody to relax? Would the scientific sessions in the afternoon be in a lay language and easy to follow? Would the technical equipment and internet reliably function? Would the simultaneous translation from English to German and vice versa make the attendees discuss in the plenary despite their earphones?



These were questions some of us asked themselves slightly nervous on the morning of the 11th of May. As a patient and as one of the organizers I may answer these questions with “YES”! Fortunately “yes” to all of them as the evaluation forms of the participants told us afterwards.

With more than 50 participants from Germany, United Kingdom, Spain, Argentina, Denmark, Netherlands and Sweden and even with a lady from Mexico connected by Skype we began our event. As a patient, I felt quite familiar in a conference room filled with people all related to MDS. It was a great place to be for information and support. Although I am in my eighth year of the disease and though I am certainly well educated on my diagnosis, I still got a variety of useful answers over the day from other patients and caregivers based on their own research and personal experience.

In the first block of the morning we focused on the importance of patient organizations. German and English representatives spoke about their commitment for patients and family members. In a team we then held our quality-of-life session with questions like “What if you wake up and your MDS is gone, how would you react?” “Despite MDS what’s on your bucket-list?” “What does quality of life mean to you?” Interaction and discussion were good and emotional. We shared one and a half valuable hours.

The original Spanish MDS awareness film, presented in English with German subtitles, was a five minute attraction for the attendees. The film was presented by the representative of AEAL, the Spanish patient organization, and it touched people’s hearts.

In the movie, a young waiter and an elderly customer are having a short conversation in a café. The customer turns out to be an MDS patient, who has been taking a new drug for a while making him red blood cell transfusion independent. He again is able even to travel, having regained a lot of his old stamina. Also the

father of the waiter obviously suffers from MDS, but he is much worse off. “Ask your doctor then, he should know about”, is the last sentence of the customer. Hearing the good news the waiter runs to his father to tell him about the possibility of a potential therapy. Here the film ends. It is not about any specific or real drug. But it’s why you should want as much information about treatment options as possible. Ask your doctor and talk to MDS fellows! Be persistent and inquisitive!

In the afternoon, we were proud of having two very reputable MDS experts with us: Professor U. Platzbecker (Dresden) and Professor A. Giagounidis (Düsseldorf). Their session covered the most common and current treatment options, including the likelihood of response for low and high risk MDS patients. Even new investigational drugs were discussed. Eligibility for trials and criteria to be a possible transplant candidate were further important issues.

The two professors presented their session in a dialogue manner: easy to follow, lay language, relaxed and cool, but on the other hand high-standard, interesting and informative. More than we ever had expected from a scientific session. Thank you very much ! The audience was excited.

Another highlight was our MDS Quiz “MDS-Verstehen” in English “To understand MDS” or shorter “MDS-Genius”. This game in the “Who Wants To Be A Millionaire” style can be played on three levels to extend one’s knowledge of the disease and its context (<http://quiz.mds-patienten-ig.org>). People at the patients’ day liked it very much and played it during



the breaks. Due to the support of CELGENE we were able to install this game properly in German language.

After the official end of the patients’ event there was a lot of informal networking going on between those committed to MDS for at least one more hour. The library of our German patients’ organization MDS-PAT-IG booth had a lot of printed material about MDS to offer. There you also could find the printed drafts of the “Building Blocks of Hope” published by the MDS Foundation in German. MDS people were very interested in the booklet.

To Learn From the Patients’ Day

It was not my first patients’ day, so by comparing I can tell, it was a very successful one. Why? Through the QoL session, we made patients and their caregivers exchange crucial experience of leading their life despite MDS. Once having talked to one another, many patients or partners felt self-confident enough to talk in front of the plenary. It became evident that partners and family have a lot of power to research, to be an advocate of the patient, to participate in treatment decisions and to work with the doctors. Patient days should not only live on external scientific talks of the physicians, but develop their synergy from the concerns and needs and above all from the personal experience and knowledge of the patients and their families. Many patients’ days only offer a

Q&A panel of the physicians at the end of the event, when everybody is already tired or when there are only a few minutes left to ask questions in between two scientific oral presentations in a row. Patients only have time to get to know each other during the lunch and coffee breaks. No, what we need are self-educational patient-blocks embedded in the program! And also patients on the panel! Patients definitely benefit from “working” with other patients.



As our two professors demonstrated by their scientific dialogue session there are diverting alternatives to educate on the MDS disease than mere frontal teaching. The goal must be to catch the audience’s attention and to keep it over the session. This means thinking about teaching methods is a must. Too much external input will not lead to well-educated and compliant patients, but a well-balanced mixture of exchange, input and support will do the job. The results on our evaluation forms confirmed that we were on the right way.

You should want as much information about treatment options as possible. Ask your doctor and talk to MDS fellows! Be persistent and inquisitive!

Personal Note

I was supposed to meet my MDS fellow and soul mate Bob Weinberg in Berlin, long-standing board member of the MDS Foundation. At ASH in December 2012 in Atlanta we made plans to do some sightseeing in Berlin together after the official Symposium and after the patients' event. I would have started our tour with the Memorial of the Resistance-Fighters against Hitler on July, 20th 1944 just opposite the Hotel Maritim in the

Stauffenberg-Street. But Bob could not come. After 15 years of low-risk-MDS his disease converted to AML in February 2013 and, being scheduled for a transplant, he died from the high intensity chemo in April. I was not the only one who missed him terribly at the Symposium and at the Patients' Forum. He would have contributed a lot, as he always had done before. But I hope he looked down on all of us in the Maritim's united in the fight against MDS and said: "Well done!".



YOUNG INVESTIGATOR GRANT PROGRAM



2013 Young Investigator Grant Winners:

Dr. Hideki Makishima accepting the award on behalf of Chantana Rakpan (L) and Taly Glaubach, MD (R)

Congratulations

Young Investigator Grant Winners!

Chantana Rakpan, MD
Cleveland Clinic

Taly Glaubach, MD
Anne and Robert H. Lurie Children's Hospital of Chicago

We would like to thank Gabrielle's Angel Foundation for Cancer Research for their generous grant in the support of young investigators through the MDS Foundation.



ABOUT THE FOUNDATION

Who Are We?

The MDS Foundation, Inc. is an international organization established in 1994 by world renowned researchers dedicated to further scientific knowledge, patient support, and education in the myelodysplastic syndromes (MDS). The Foundation is based on the premise that international cooperation will accelerate the process leading to the control and cure of MDS.

What is MDS?

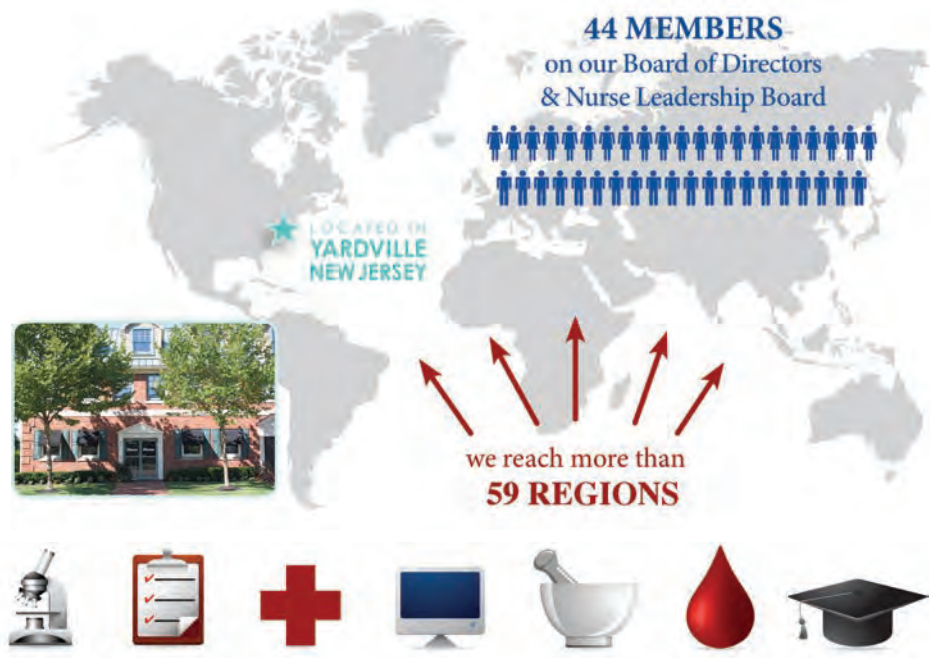
The myelodysplastic syndromes are a group of bone marrow disorders resulting in the ineffective production of normal mature blood cells. Many patients experience anemia from the lack of effective red blood cells, thereby requiring frequent blood transfusions. A shortage of white blood cells may cause malfunctioning of the immune system resulting in infections. Insufficient platelets can result in excessive bleeding. In about one-third of MDS patients, the disease transforms into acute myelogenous leukemia (also known as AML).

What We Do

The MDS Foundation provides research grants for scientific investigators, sponsors international working groups of scientists and physicians to further diagnostic, prognostic and treatment techniques, and disseminates information on state-of-the-art research, clinical trials and treatments among the professional and patient communities. The Foundation also refers patients to its collection of "MDS Centers of Excellence," maintains an electronic forum on its website for interaction and support among patients, and provides educational programs for both health care professionals and patients and their families.

Where We Are

The Foundation is located in Yardville, New Jersey and is active in more than 59 regions around the world. Our Board of Directors consists, for the most part, of



physicians and nurses actively engaged in searching for a cure of the disease. Our Nurse Leadership Board is comprised of specialized nurses sharing information and teaching others how to care for MDS patients. Together, the Board of Directors and the Nurse Leadership Board consist of 44 members representing 14 countries. Please see our website www.mds-foundation.org for a complete list of our board members and other vital information about the disease and the Foundation.

Our Fundraising Efforts

As a tax exempt non-profit, section 501(c)3 organization, donations to the MDS Foundation qualify for a U.S. tax deduction (it is essential to consult with your tax advisor to confirm your own tax situation). The MDS Foundation actively seeks financial support for our mission and programs to continue providing services such as the following:

- International Working Group for Prognosis in MDS (IWG-PM)
- Young Investigator Research Grants
- Hot-line for patients and caregivers to speak with our Patient Liaison at 800-MDS-0839

- Numerous Face to Face Patient Forums in multiple cities with presentations by local physicians
- Online Patient Forum monitored by experts
- Designation of Centers of Excellence (COE) meeting the highest standards for diagnosis, treatment, and patient care
- Patient Referrals to COEs
- *Building Blocks of Hope*® handbook (in print or online) with complete written and video information on the care and treatment of MDS
- The MDS News Email Alerts
- Biennial International MDS Symposia for professionals & continuing medical and nursing education programs

Donations can be made on our website by credit card (through PayPal), or by check made payable and addressed to:

**The MDS Foundation, Inc.
4573 South Broad St.
Suite 150
Yardville, New Jersey 08620**

www.mds-foundation.org

MEETING HIGHLIGHTS AND ANNOUNCEMENTS

THE AMERICAN SOCIETY OF HEMATOLOGY 54TH ANNUAL MEETING & EXPOSITION • DECEMBER 2013

On behalf of the MDS Foundation and our Board of Directors, please join us for our upcoming Satellite Symposium:

Major Therapeutic and Molecular Advances in MDS

Friday, December 6, 2013
7:00–11:00 am

Hilton New Orleans Riverside
New Orleans, Louisiana

TARGET AUDIENCE

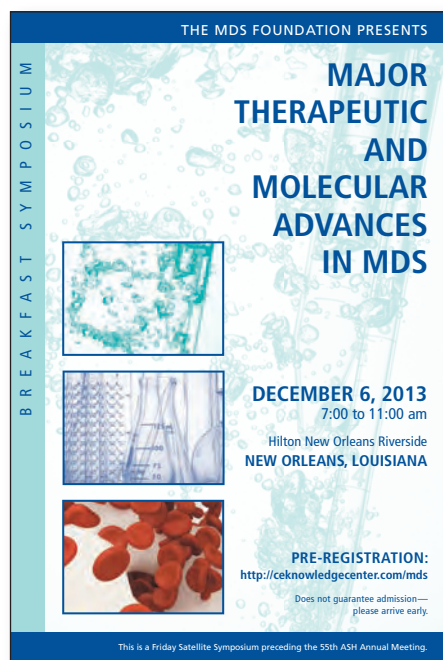
This activity is intended for physicians, oncology nurses, nurse practitioners, physician assistants, and other health care professionals interested in the treatment and management of patients with Myelodysplastic Syndromes.

LEARNING OBJECTIVES

Upon completion of this course, the participant will be better able to:

- To understand the clinical and biologic features which are useful for classifying MDS and aid in therapeutic decision-making.
- To understand the current therapeutic options for MDS patients whose disease has not responded to standard therapy.
- To know the current status of treatments aimed at improving severe thrombocytopenia in MDS patients.
- To understand how the use of flow cytometry aids diagnosing and assessing prognosis of MDS patients.
- To understand the impact of microenvironmental abnormalities on hematopoiesis in MDS.
- To understand pathogenetic molecular features contributing to MDS progression.

**VISIT THE
MDS FOUNDATION BOOTH:
#2813**



PROGRAM OVERVIEW

Recent developments in clinical, immunophenotypic, and molecular risk analyses have generated major advances for aiding management of patients with myelodysplastic syndromes (MDS). These methods and current therapies, with novel agents and their combinations, will be discussed. Also discussed will be the biologic implications of marrow cell molecular mutations and micro-environmental abnormalities for improving the understanding of pathogenetic lesions underlying this disease.

FACULTY

Benjamin Ebert, MD, PhD
Brigham and Women's Hospital
Boston, MA

Pierre Fenaux, MD, PhD
Hôpital St Louis, Paris 7 University
Paris, France

Peter Greenberg, MD
Stanford University Cancer Center
Stanford, CA

David Scadden, MD

Massachusetts General Hospital Center
for Regenerative Medicine
Boston, MA

Arjan van de Loosdrecht, MD, PhD

VU University Medical Center
Amsterdam, The Netherlands

AGENDA

7:30 am – 7:40 am

Program Overview and Objectives

7:40 am – 8:15 am

**Prognostic Scoring Systems for
Therapeutic Decision-making in
MDS Patients**

Peter Greenberg, MD

8:15 am – 8:50 am

**Novel Agents and Combinations for the
Treatment of MDS (including updated
results of thrombopoietin receptor
agonist trials in MDS)**

Pierre Fenaux, MD, PhD

8:50 am – 9:25 am

**Improving the Role of Flow Cytometry
for the Characterization of MDS**

Arjan van de Loosdrecht, MD, PhD

9:25 am – 10:00 am

**Marrow Microenvironmental
Abnormalities in MDS**

David Scadden, MD

10:00 am – 10:35 am

**Molecular Abnormalities and
their Impact on Prognosis of MDS**

Benjamin Ebert, MD, PhD

10:35 am – 11:00 am

Questions/Answers/Discussion



THE 13TH INTERNATIONAL SYMPOSIUM ON MYELOYDYSPLASTIC SYNDROMES



Advancing Research & Patient Care

THE 13TH INTERNATIONAL SYMPOSIUM ON MYELOYDYSPLASTIC SYNDROMES

Washington, D.C., U.S.A.
APRIL 29 - MAY 2, 2015



MDS 2015 Symposium Secretariat
c/o Kenes International
Email: mds@kenes.com
For MDS Foundation Contact:
US number: 1-800-MDS-0839
Outside the US: 1-609-298-1035

www.kenes.com/mds

Foundation Plans International Symposia Through 2017

The MDS Foundation has approved applications for the next two International Symposia. These symposia are scheduled for 2015 in Washington, DC, and 2017 in Valencia, Spain.



2015 – PLAN TO ATTEND

*The 13th International Symposium on MDS
April 29 – May 2, 2015 • Washington, DC USA
Chairman: Steven D. Gore, MD*



2017 – PLAN TO ATTEND

*The 14th International Symposium on MDS
Spring 2017 • Valencia, Spain
Chairman: Guillermo Sanz, MD*

PRACTICE AND TREATMENT SURVEYS

MDS PRACTICE AND TREATMENT SURVEY FOR HEALTHCARE PROFESSIONALS

**In 15 Minutes You Can Help Improve The Diagnosis
and Treatment of MDS Patients**



The myelodysplastic syndromes (MDS) are a heterogeneous group of myeloid malignancies with variability in clinical presentation, disease trajectory, treatment goals, and expected outcomes. Therefore, the treatment of patients with

myelodysplastic syndromes (MDS) often differs from patient to patient. Outcomes for patients with MDS can be enhanced through the use of individualized, risk-adapted strategies for treatment which take into account the treatment goals based on a patient's risk status. The International Prognostic Scoring System (IPSS) has been recently revised (IPSS-R) with modified risk attributes and corresponding risk categories. This survey is designed to evaluate current health care provider practice patterns for the diagnosis and treatment of MDS. Case studies are included to investigate familiarity and application of the IPSS and IPSS-R. The MDS Foundation will compile the results and will provide a summary of the findings on the MDS Foundation website. We appreciate you taking the time to complete this survey.

Access This Link to Complete Your Survey:
<https://www.surveymonkey.com/s/MDSF-PTSsurvey>

MDS PATIENT QUALITY OF LIFE SURVEY

Thank you so much for participating in this very important survey. We are looking forward to learning from you about the impact that MDS has on your quality of life.



This questionnaire contains questions concerning your MDS symptoms, the treatment you are receiving, and the impact that MDS and treatment may have on your life.

There is no right or wrong answer. Please do your best in providing a response to each question.

Your responses will be kept confidential and will only be reported in combination with the results from other MDS patients who participate in this survey.

The information that we gather from this survey will be used to develop programs to assist patients and their families, to educate physicians, nurses, and other allied healthcare professionals, and to work with governmental and private agencies/companies to provide better care and service to you, the MDS patient.

Thank you again for your participation!

Access This Link to Complete Your Survey:
<https://www.surveymonkey.com/s/MDSPatientQoLSurvey>

FROM THE FOUNDATION

BUILDING BLOCKS OF HOPE



A global MDS Foundation print and online patient advocacy initiative, providing a personalized educational program for the patient and caregiver to prepare, participate, and **LIVE** with MDS.

Strategies for Patients and Caregivers **LIVING** with MDS

On behalf of Sandra Kurtin and The MDS Foundation we are pleased to announce the arrival of the **BUILDING BLOCKS OF HOPE**, a global print and online patient advocacy initiative, providing a personalized educational program for the patient and caregiver to prepare, participate, and **LIVE** with MDS.

The digital book is quite striking and easy to read online. To view the digital version of the Building Blocks of Hope, please use the following link:

<http://buildingblocksofhope.com>

If you would like to download the Building Blocks of Hope for printing and personalization, please use the following link: http://www.mds-foundation.org/wp-content/uploads/2013/03/BBOH_2013_Handbook_full-book_lores.pdf.

We will be working with the MDS Foundation Board of Directors, International Nurse Leadership Board (MDSF-NLB) and colleagues from our MDS Centers of Excellence to translate and adapt the Building Blocks of Hope (BBoH) into multiple languages in order to reach as many MDS patients as possible. We are currently translating the BBoH into French, German and Spanish. We will also be adapting the English version for MDS patients in the UK and Canada. Once

"It took me three days, but I have read the entire BBOH book. **What a magnificent undertaking on your part.**

Your book is the most comprehensive source I have read. My understanding of MDS and possible treatment options has been greatly increased. Thank you for all your work.



– Steve Siehr

A PRINT AND ONLINE EDUCATIONAL TOOL

- You can conduct a search using key phrases which will highlight any page that includes that phrase.
- Individual pages can be printed to create a personalized educational tool.
- My MDS Plan, in particular, can serve as a useful tool for patients to track their progress and organize their information.
- You will find embedded videos and slide sets, in the digital version, to augment patient and caregiver education.
- You can link directly to global resources for clinical trials, drug information, bone marrow transplant services, and other support services.

these translations are complete they will be added to our website.

The online versions of the BBoH will be accessible to you at any time, and the pdf format can be downloaded for local use. Although these pages are copyrighted, we extend an invitation to print

and distribute individual pages, without modification, as needed to support patients and caregivers **LIVING** with MDS!

Translations in Danish, French, German, and Spanish coming soon! Canadian Adaptation available now.

IT HAS ARRIVED — THE MDS CLINICAL TOOLBOX

Practical Tools for Clinical Management of MDS



mds foundation
the myelodysplastic syndromes foundation, inc.

MDS - A bone marrow failure disorder

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THE MDS ACADEMY
AN INTERACTIVE PROFESSIONAL EDUCATIONAL PROGRAM

Welcome to the MDS Academy Clinical Toolbox.

Publications
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Professional Education
Video Lectures, Slide Sets with Audio, and Educational Calendar
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Patient & Caregiver Resources
Building Blocks of Hope, Patient Forums, Support Groups, MY MDS Plan, and more...
[View all resources](#)

Interactive Tools
IPSS-R Calculator, MDS Health Tracker and other resources
[View all tools](#)

MDS Centers of Excellence
[Find a CoE near you!](#)

Clinical Trials
Information about what will be on the Clinical Trials page
[Learn more](#)

A variety of clinical tools that will be maintained on the MDS Foundation website including the IPSS-R calculator, summaries of the most recent published data, links to other online resources and tools to assist patients/caregivers to take an active role in their MDS care.

MDS AWARENESS

BECOME AN MDS ADVOCATE TODAY!

Have You Told Someone About The MDS Foundation?



Spreading Awareness Any Way You Can – Thank You Austin Pearson and Michigan State University!

MDS FOUNDATION STORE

NEW MDS AWARENESS ITEMS AVAILABLE!

New MDS awareness items are now available through our online store and our popular Hope for MDS wristbands are still available. Have you told someone about the MDS Foundation recently? Help promote MDS awareness any way you can and purchase your items today! For a donation of your choice, receive your custom item(s) as a “Thank You” for your generosity.



3 WAYS TO ORDER:

1. **ONLINE** ► CLICK to SHOP ►
<http://www.mds-foundation.org/merchandise/>
2. **BY PHONE** with credit card at
800-MDS(637)-0839
3. **BY MAIL** with check enclosed to:
The MDS Foundation, Inc.
4573 South Broad Street, Suite 150
Yardville, NJ 08620

Raising awareness is a year-round job!

Thank you for your support.

IN MEMORY OF ROBERT WEINBERG

The MDS Foundation Remembers Bob...

Earlier this year, the MDS Foundation and the larger community of MDS patients, caregivers, physicians, nurses and patient/health care advocates lost a dear friend and indefatigable supporter, advocate, and colleague, Robert (Bob) Weinberg. Bob lost his battle with MDS, which evolved to an acute leukemia that was unresponsive to therapy.

Bob served on the Board of Directors of the MDS Foundation since 2001 and on its Executive Committee since 2010. He was an attorney who practiced law at Pepper Hamilton LLP in Philadelphia. When Bob was diagnosed with MDS in 1998, he sought out the Foundation and became its most active, non-physician Board member.

Bob worked tirelessly for the Board; he was involved in every one of its functions – drafting by-laws, overseeing our financial statements, reviewing our finances and our communications with the community, making sure that the website and our patient information line provided clear and accurate advice, helping us pick the sites where the meetings were held, organizing and choosing locations for the patient forums, and of critical importance, serving as a clear voice and advocate for MDS patients to the Board.

Whenever heavy lifting was required, Bob was always the first to volunteer or to make sure that the physician volunteers functioned as a team, in an effective and communicative way. Bob was a superb communicator, and he helped us all, in countless ways, with small and large acts of kindness, with his insights and energy, and with his human touch, his powerful humanity.

Bob's wife, Rochelle, and his daughter, Daniella, have vowed to help the Foundation in its mission to aid in the education of the public about MDS and in the education of health care professionals, and to support the research and researchers who are striving to better understand this disease and advance new cures. Bob loved his dogs Milkshake and Cognac, he loved his family, his life and he loved us. We miss him very much.



As a Nurse and Nurse Practitioner working with cancer patients, including patients with MDS, for almost 30 years, I have met some amazing individuals who inspire me to continue my work in this field. Robert Weinberg, or as I knew him Bob, was one of those individuals. Bob was diagnosed with MDS in 1998 at the age of 48 when we knew very little about this disease. From the day he was diagnosed, Bob became one of the greatest advocates for patients and caregivers living with MDS. He worked tirelessly promoting scientific discovery in the hope of improving the lives of all patients with MDS. He joined with the MDS Foundation and offered his insights and services as a way to achieve these goals.

I first met Bob in 2005 as a volunteer member of a newly developed nursing advisory board. Over the past eight years Bob continued to inspire me. He was always in support of oncology nursing offering encouragement and congratulations to the members of the MDS Foundation Nurse Leadership Board for their work in support of MDS patients, their caregivers, and oncology professionals. He continually worked to find better ways to support MDS patients and their caregivers, and donated his time generously toward finding better ways to treat and support patients with MDS. Bob graciously shared his journey in two testimonials which have been included in the Building Blocks of Hope program (www.buildingblocksofhope.com). He loved his family, his dogs (Milkshake and Cognac), and will always hold a special place in my heart.

In fond memory of Bob Weinberg, Sandy Kurtin

REPRINTED FROM:
PRESS OF ATLANTIC CITY

Margate Woman Commits to Aid Families Dealing With MDS

ELISA LALA

Staff Writer

Wednesday, August 7, 2013

When a person is diagnosed with a life-threatening illness, the whole family suffers.

Understanding this on a personal level, Margate resident Rochelle Ostroff-Weinberg recently held a support group for spouses and loved ones of people with MDS in her living room.

She is the widow of Robert J. Weinberg, who died in April after fighting myelodysplastic syndrome, or MDS, for 15 years.

The event, held July 27, was called “The MDS Spouse: Coping and Caring” and Rochelle said its purpose was twofold:

First, to pass on the knowledge she and her family acquired during the years of coping and coming to terms with her husband’s illness.

“The other family members can feel lost, helpless, scared, worried, traumatized, confused or conflicted,” Rochelle said. “I know personally. Bob had MDS for 15 years. I am a veteran spouse.”

Second, to continue to support the MDS Foundation, which Robert was involved with as an executive board member.



Rochelle Ostroff-Weinberg hosted an MDS Support Group meeting in her home in July.

“At Bob’s funeral, I set a promise in front of 150 people present to do good, important work for and through the MDS Foundation,” Rochelle said. “Yet, I wanted to make it mine and something that would reflect a component of support needs to which I related personally and genuinely. I see that as my role now, to reach out to others who share—are living through—a similar experience.”

The MDS Foundation, established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS, was the first foundation in the world dedicated solely to this disorder. Robin Roberts, the anchor of ABC’s morning show Good Morning America, also had MDS.

Rochelle said the support group was both well-received and well-attended by the community and she plans to host more, possibly in October and April.

Support group attendee Jimmy Wong, the son of an MDS patient who died in January noted, “It was great to share and experience with others who are living with MDS,” he said. “It was hopeful to see others still living a good quality of life with MDS.”

To learn more about the MDS Foundation or the disorder, visit www.mds-foundation.org.



Tania and Jimmy Wong, surviving wife and son of MDS patient German Wong.

REFERENCES IN MDS

Highlights of Latest Literature in MDS

Suneel D. Mundle, PhD
Rhea Mundle

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**.

EPIDEMIOLOGY AND OUTCOMES RESEARCH:

1. Sperr W et al. Proposed score for survival of patients with myelodysplastic syndromes. *Eur J Clin Invest*. 2013;43(11):1120–1128 (<http://www.ncbi.nlm.nih.gov/pubmed/24102333>)

Analysis of IPSS-related and -independent variables in 400 patients with primary MDS within Austrian MDS platform in a multivariate analysis demonstrated that IPSS, ferritin ($>$ or ≤ 900 ng•mL), age (< 70 , $70-79$ or > 80 years) and HCT-CI comorbidity had survival predictive value. Using a scoring system with these variables 4 survival risk groups could be stratified.

2. Lucioni C et al. Costs and quality of life in patients with myelodysplastic syndromes *Am J Blood Res*. 2013;3(3): 246–259 (<http://www.ncbi.nlm.nih.gov/pubmed/23997987>)

Analysis of 17 eligible studies from literature search demonstrated that the total medical costs per patient per year ranged from approximately \$10,000–20,000 in transfusion independent patients to \$30,000–50,000 in transfusion dependent cases, with a reduction in quality of life to half during development of transfusion dependence.

DIAGNOSIS/PROGNOSIS:

1. Voso M et al. Revised international prognostic scoring system (IPSS) predicts survival and leukemic evolution of myelodysplastic syndromes significantly better than IPSS and WHO prognostic scoring system: validation by the Gruppo Romano Mielodisplasie Italian regional database.

J Clin Oncol. 2013;31(21):2671–2677. (<http://www.ncbi.nlm.nih.gov/pubmed/23796988>)

A revised IPSS (IPSS-R) scoring system was reported in 2012, which included both disease and patient related parameters. It broadened consideration for cytogenetic abnormalities and severity of cytopenias. In the present validation study, IPSS-R was applied to 380 MDS cases in Italian regional database enrolling patients from the city of Rome. When compared with IPSS and WPSS, the predictive ability for overall survival and leukemic transformation were both significantly superior with IPSS-R ($P < 0.001$ vs. IPSS or WPSS).

TREATMENT:

IMiDs:

1. Caceres G et al. TP53 suppression promotes erythropoiesis in del (5q) MDS, suggesting a targeted therapeutic strategy in lenalidomide-resistant patients. *Proc Natl Acad Sci USA*. 2013; 110(40):16127–16132. (<http://www.ncbi.nlm.nih.gov/pubmed/24043769>)

Cenersen; a 20-mer antisense oligonucleotide complementary to TP53 exon 10, was shown to suppress nuclear p53 in CD34+ cells isolated from del (5q) patients with a proportionate increase in erythroid burst recovery in vitro. This was corroborated by addition of an indirect p53 suppressor dexamethasone to lower risk transfusion dependent del (5q) patients with acquired drug resistance. Along with cellular p53 suppression and expansion of erythroid precursors, in 5 of the 8 treated patients, transfusion independence could be restored.

Demethylating Agents:

1. Li X et al. Cytogenetic response based on revised IPSS cytogenetic risk stratification and minimal residual disease monitoring by FISH in MDS patients treated with low-dose decitabine *Leuk Res*. 2013; Sept 18 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/24084368>)

Response analysis was conducted based on revised IPSS cytogenetic risk stratification in 87 MDS patients treated with low dose decitabine ($15-20$ mg/m²/d $\times 5$ per course). Among patients with abnormal cytogenetics the overall response rate was approximately 61% with 41% achieving complete cytogenetic response. Survival was significantly better in cytogenetic responders and the survival in poor/very poor karyotype patients was comparable to those with good/very good karyotypes.

2. Duong V et al. Poor outcome of patients with myelodysplastic syndrome after azacytidine treatment failure. *Clin Lymphoma Myeloma Leuk*. 2013; Sept 17 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/240541590>)

This retrospective single institution study with 59 patients showed that in salvage therapy after azacytidine failure 31% response was obtained with intensive chemotherapy, while no response was seen with decitabine. Median overall survival for the entire cohort after azacytidine failure was 5.8 months.

3. Xicoy B et al. Results of treatment with azacitidine in patients aged ≥ 75 years included in the Spanish registry of myelodysplastic syndromes. *Leuk Lymphoma*. 2013; Sept 16 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/23952246>)

One hundred seven MDS patients ≥ 75 years age within Spanish registry that were treated with azacitidine, were found to have transfusion independence achieved in 40% cases in whom median survival of 22 months was superior to those that did not achieve transfusion independence. The median number of treatment cycles received were 8 with a cycle delay occurring in 29% cases and 47% were hospitalized for infections.

Other Agents:

1. Neukirchen J et al. Real life experience with alemtuzumab treatment of patients with lower-risk MDS and a hypocellular bone marrow. *Ann Hematol*. 2013; Aug 10 [Epub ahead of

print] (<http://www.ncbi.nlm.nih.gov/pubmed/23934199>)

Alemtuzumab (humanized anti-CD52 antibody) treatment of 9 MDS RCMD cases demonstrated overall response in five patients (3CR and 2 HI). The treatment was well tolerated.

2. Komrokji R et al. Phase I clinical trial of oral rigosertib in patients with myelodysplastic syndromes. *Br J Haematol.* 2013;162(4):517–524. (<http://www.ncbi.nlm.nih.gov/pubmed/23789936>)

An oral multi-kinase inhibitor rigosertib was administered to 37 MDS patients with a dose escalation design (560 mg to 700 mg bid). Dose limiting toxicity (gr 3 dysuria and shortness of breath) occurred at 700 mg bid dose level. The clinical activity included 2 marrow complete remissions in RAEB-I patients previously treated with azacitidine. In addition, 4 patients achieved transfusion independence and HI.

3. Rhyasen G et al. Targeting IRAK1 as a therapeutic approach for myelodysplastic syndrome. *Cancer Cell.* 2013; 24: 90–104 (<http://www.ncbi.nlm.nih.gov/pubmed/?term=Rhyasen+and+IRAK1>) *MDS arises from a defective hematopoietic stem/progenitor cell. Through gene expression analysis in CD34+ cells from MDS and normal marrows, it was found that IRAK1- an immune-modulating kinase- is overexpressed and hyperactivated in MDSs. IRAK1 inhibition may not affect or may actually cause a compensatory increase in pro-survival Bcl-2 expression. When IRAK1/4 and BCL2 inhibitors were combined, the cotreatment was proven to induce apoptosis and effectively eliminate MDS clones, thus making IRAK1 and Bcl-2 a drugable targets in MDS.*

PATHOBIOLOGY:

1. West R et al. Acquired ASXL1 mutations are common in patients with inherited GATA2 mutations and correlate with myeloid transformation. *Hematologica.* 2013; Sept 27. [Epub

ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/24077845>)

Somatic heterozygous ASXL1 mutations occurred in 29% of GATA-2 deficiency MDS patients. These patients with dual abnormality tended to be younger, almost exclusively female and had a high incidence transformation to proliferative chronic myelomonocytic leukemia.

2. Dimicoli S et al. Overexpression of the Toll-like receptor (TLR) signaling adaptor MYD88, but lack of genetic mutation in myelodysplastic syndromes. *PLoS One.* 2013;8(8): e71120 (<http://www.ncbi.nlm.nih.gov/pubmed/23976989>)

No genetic mutation but m-RNA overexpression for MYD88 was found in bone marrow CD34+ cells derived from MDS patients. A treatment of CD34+ cells derived from low risk MDS patients with MYD88 inhibitor led to increased erythroid colony formation indicating a therapeutic potential of MYD88 blockade strategy.

REVIEWS AND PERSPECTIVES:

The following articles provide significant review of literature and/or innovative perspective on the state-of-the-art in MDS and identify need for additional prospective studies.

1. Zeidan AM, Linhares Y and Gore SD. Current therapy of myelodysplastic syndromes. *Blood Rev.* 2013;27(5): 243–259 (<http://www.ncbi.nlm.nih.gov/pubmed/23954262>)
2. Kulasekaraj AG, Mohamedali AM, Mufti GJ. Recent advances in understanding the molecular pathogenesis of myelodysplastic syndromes. *Br J Haematol.* 2013;162(5):587–605. (<http://www.ncbi.nlm.nih.gov/pubmed/23869491>)
3. Greenberg PL et al. Myelodysplastic syndromes: clinical practice guidelines in oncology. *J Natl Compr Canc Netw.* 2013;11(7):838–874. (<http://www.ncbi.nlm.nih.gov/pubmed/23847220>)
4. Greenberg PL. The Multifaceted Nature of Myelodysplastic Syndromes: Clinical, Molecular and Biological Prognostic Features. *J Nat Compr Canc Netw.* 2013;11(7):877–885, (<http://www.ncbi.nlm.nih.gov/pubmed/23847221>)

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.

BRAND NEW!

Connect on our improved  PATIENT FORUM and zero in with an MDSF Expert.

Look for this new feature on our free online discussion board of information exchanged between patients, caregivers, and family members. Where else can you have MDSF Experts at your fingertips addressing your unique concerns and personally have your questions answered?

Available on mobile devices through our website

www.mds-foundation.org



PATIENTS & CAREGIVERS **LIVING WITH MDS** FORUMS

SPREADING THE NEWS WORLDWIDE



**HIGHLIGHTS FROM OUR
2013 INTERNATIONAL
MDS FORUMS**

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Atlanta, GA ■ Berlin, Germany
Detroit, MI ■ Chicago, IL ■ Rochester, NY
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Long Island, NY ■ Indianapolis, IN



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<http://www.mds-foundation.org/events> and FACEBOOK
FOR OUR FREE MEETINGS TAKING PLACE IN A CITY NEAR YOU!

PEOPLE HELPING PEOPLE...

Established MDS Patient Support Groups

United States

- **Chicago, Illinois MDS 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.
- **Lakeland, Florida Regional MDS Support Group:** For more information call Vivian Paul at 863-698-5137 or Kathe Dempster at 863-816-8482.
- **New York, New York MDS Support Group:** Contact the group facilitator, Lisa Tomcykoski at drtomcykoski@yahoo.com for further details.
- **Philadelphia, Pennsylvania MDS Support Group:** For more information call the MDS Foundation at 800-MDS(637)-0839 or email Audrey Hassan at ahassan@mds-foundation.org.
- **Puget Sound MDS Support Group:** For more information call Janine Kowack at 206-992-0609 or email jkowack@comcast.net.
- **Southern California MDS Support Group:** Meets on the third Saturday of the month at St. Mary Star of the Sea Church, 609 Pier View Way, Oceanside, CA 92054 at 2:30 PM. Contact Susan Pope at smpopes@gmail.com or call: 760-744-7665.
- **Stanford Cancer Center MDS Patient & Family Support Group:** Meets the first Friday of the month from 1:30–3:00 pm at the Stanford Cancer Center, 875 Blake Wilbur Drive, Palo Alto, California, 2nd Floor Conference Room CC2105. Contact Group Leader, Lenn Fechter, RN, BSN at: 650-725-0744.
- **Folsom, California MDS Support Group:** For more information call Jalil Fardanesh at 916-984-6468, email jfardanesh@gmail.com.

International

- **Belgium:** Belgische MDS Contactgroep, <http://mds-foundation.org/psg/vlaamse>
- **Canada:** Hamilton, Ontario MDS Support Group <http://mds-foundation.org/psg/cpsghhs>; Toronto, Ontario MDS Support Group, <http://mds-foundation.org/psg/cpsgt>
- **Czech Republic:** Sdruzeni MDS, <http://www.diagnoza-mds.cz>
- **Denmark:** MDS DK Patientstøttegrupper, <http://www.mds-and-you.info>
- **France:** Association Connaître et Combattre les Myélodysplasies, <http://asso.orpha.net/CCM>
- **Germany:** MDS-Net Deutschland, <http://www.mds-net-de.org>; MDS-Patienten Interessengemeinschaft (MDS-PAT-IG) <http://www.mds-patienten-ig.org>
- **Hungary:** Magyar Betegsegítő Csoport, <http://mdsfoundation.org/psg/magyarbc>
- **Japan:** Japan MDS Patient Support Group, <http://www.mdssupport.net>; MDS Renrakukai, <http://www.geocities.jp/mdsrenraku>
- **United Kingdom:** UK MDS Patient Support Group, <http://www.mdspatientsupport.org.uk>

Global MDS Patient Support Groups

The overwhelming success of our *Patients & Caregivers LIVING with MDS Forums*, which allowed patients to meet peers who live in their community, has led us to create permanent support groups worldwide. If you are interested in joining a few other people to help start a needed support group for MDS in your area, please contact us today.

2013 HUNGARIAN MDS PATIENT SUPPORT GROUP



2013 1ST DANISH MDS PATIENT SUPPORT GROUP



Featured MDS Patient Support Group: Kanagawa, Japan

Kiyoyuki Ogata, MD, FACP

Metropolitan Research Center
for Blood Disorders
Shin-Yurigaoka General Hospital

The report of their first regional meeting:

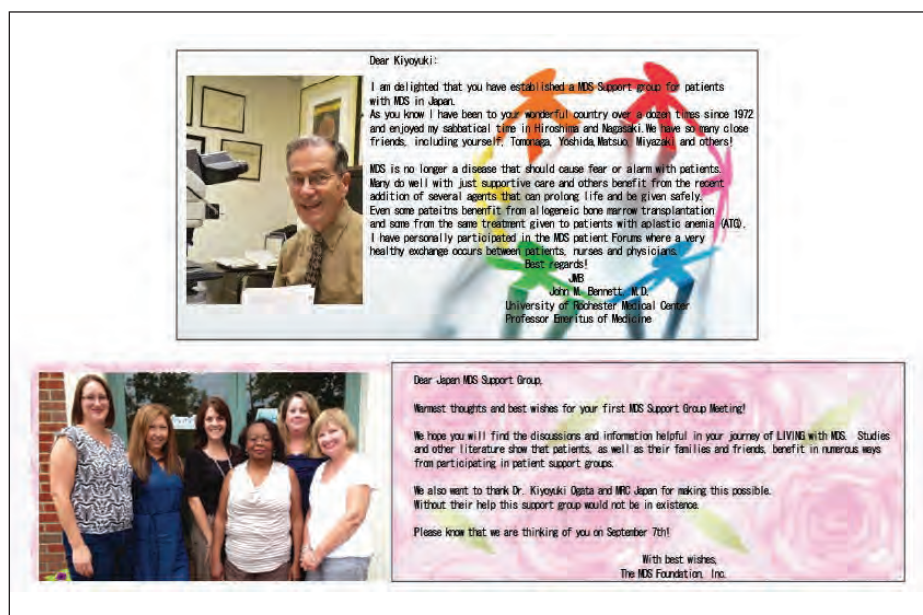
Twenty-nine MDS patients and their families gathered on that meeting. We gave seven talks to them and answered many questions asked by them. After that, we enjoyed free time with drinks and cakes and a mini violin concert by my niece, Micca. Three hours passed quickly, and we are sure that the first meeting is successful and useful for participants. We received many very positive responses from participants.



Our seven talks were:

1. **The Reason Why We Need This MDS Patient Support Group**
Mika Kojima
2. **Understanding of MDS**
Kiyoyuki Ogata
3. **MDS Flow Cytometry**
Eri Kashiwagi
4. **Fact of Stem Cell Transplant for MDS**
Kiyoyuki Ogata
5. **Living with MDS: A Story of Robert Weinberg**
Miki Iizuka
6. **Current Therapy for MDS**
Kiyoyuki Ogata
7. **Future Perspective**
Kiyoyuki Ogata

The next regional meeting will be held on November 30, 2013 at the same time and the same place.



PATIENT AND FAMILY CONTRIBUTIONS

PATIENT TESTIMONIALS

Patients Speak Out...

"The conference at Emory University for MDS patients and caregivers today was informative and it was great to meet and share stories with other MDS patients (even if I was the youngest MDS patient at the conference)."

I hope you come back to Atlanta next year.

Jennifer Greer Trotter

"Thanks for making such an extensive resource (The Building Blocks of Hope) available to the patient community."

Neil Cuadra

"I have well received the Building Blocks of Hope binder. It is an impressive piece of work conveying a mass of information to patients and caregivers."

Congratulations to the authors.

Patrick Festy

"I just wanted to thank you again for all your support that you have given me for the past year. I so appreciate it."

Susan Urban

My mom was diagnosed with MDS type RARS in October 2012 after 2 yrs of extreme fatigue. She got to the point of not being able to even make her own bed after being "super-mom" for 36 years.

"Upon this scary diagnosis, your site has been invaluable. Thank you for allowing us to actually understand what MDS is all about."

Kimberly Arment

"Amazing book Building Blocks. Wish I had it years ago! Can't wait to read more thoroughly."

Korey Yamagata

"BBoH – EXCELLENT!!!"

Ray Hershman

"I'm looking forward to the meeting in Chicago and to reading the Building Blocks of Hope."

I'm 71 years old and was diagnosed in 2008 with MDS 5q deletion. Thank you for all your info.

Linda Heller

"You have got to know you have been a big part in helping me advocate on my behalf."

I miss Kirby Stone so very much, but without you bringing him into my life I could not have moved forward with getting what I needed medically. Thank you with all my heart.

Krystal Dak

"Building Blocks of Hope is great."

I have only glanced at it on my phone but without a doubt, it is the most comprehensive information I have found on MDS.

Beth Mascia

"I received the Building Blocks of Hope. It was the most informative thing I have read about MDS."

Everyone should send away for it. They won't be disappointed."

Pat Thompson

"Building Blocks of Hope: Whoever did this web "story" should be thanked by everyone who uses it."

It is fantastic!!! Thank you for spreading this valuable information. The approach was unique and interesting to follow and explore."

Raymond W. Malles

"What a magnificent undertaking on your part."

Your book is the most comprehensive source I have read. My understanding of MDS and possible treatment options have greatly increased. Thank you for all your work.

Steve Siehr

See BBoH on page 13.



**HEALTHY BODY
HEALTHY MIND**

New Ways to Manage MDS – A New Resource For Patients and Loved Ones

A diagnosis of Myelodysplastic Syndrome (MDS) can be confusing, but arming yourself with the information necessary to understand your diagnosis is the first step toward making the treatment choice that is right for you. A new MDS-specific episode of **HEALTHY BODY, HEALTHY MIND**—a health and wellness program on public television—serves as an educational resource for the entire MDS Community.

Whether you need guidance navigating your diagnosis or you're trying to help family and friends understand what you're going through, the episode, titled "New Ways to Manage MDS," provides perspective and reassurance. Three patient stories, coupled with key facts about the latest treatment strategies, highlight unique experiences with MDS. Interviews featuring experts Dr. David Steensma, Dana-Farber Cancer Institute, United States, Dr. Aristoteles Giagounidis, St. Mary's Hospital, Germany, and Dr. Valeria Santini, Careggi Hospital, Italy share additional insight on the value of active management regardless of age along with the individualized treatment options patients should be aware of.

To view this episode online go to http://www.itvisus.com/programs/hbhm/episode_2601.asp or to order your free DVD copy today email dmurray@mds-foundation.org or call 800-MDS-0839.

A 15-year History

Hello, my name is Ryan Szanto. I am 74 years old and have been an MDS patient for 15 years. I hope to convey to you my experiences with MDS I also hope my longevity with MDS will give you hope and encouragement as you live with MDS

During a routine wellness check, I was diagnosed with anemia in July 1996. I was a very active outdoor person and did not feel there was anything wrong with me, so I did nothing about it. The next year, during another routine wellness check, the doctor wrote in red pen and circled: Significant Anemia. He recommended I see my primary doctor. I saw him in August, 1997 and had blood tests run over a 5 week period. I was told they didn't know what was wrong with me. My doctor recommended I see a hematologist/oncologist, which I did.

A bone marrow biopsy was performed and it was determined my anemia was due to MDS. The doctor had me come in once a week for a CBC for the next 15 months. In January 1999 I started on Procrit injections, 30,000 units once a week. During the next 5 years and 9 months the Procrit injections increased gradually from 30,000 to 80,000 units to keep my hemoglobin at healthy levels. In December 2005, I was switched from weekly Procrit to bi-weekly Aranesp injections. This was a blessing. The Aranesp dosage started at 300 mcg for 28 injections and now continues at 400 mcg. I have had a total of 176 Aranesp injections as of October 2012.

During a routine wellness check, I was diagnosed with anemia. I was a very active outdoor person and did not feel there was anything wrong with me, so I did nothing about it.



MDS Patient Ryan Szanto

In June 2001 I started on blood transfusions. As of October 2012 I have received 377 units of blood. By June 2004 I was in iron overload, my ferritin was 2990 due to the number of blood transfusions. I started iron chelation with a drug a called Desferal which is dispensed with an infusion pump for 12 hours a day, 5 days a week. I continued this treatment for 1 ½ years.

In the fall of 2005 the MDS Foundation notified me that there was a new oral drug, Exjade, used to treat iron overload. Exjade was up for FDA approval in Washington, D.C. and I was asked to testify as to why the drug should be approved. I was thrilled to go. It would be wonderful to get off that pump. I went with 14 other patients who also developed iron overload as a result of chronic transfusions for MDS, Aplastic Anemia and Thalassemia. Thankfully it was approved. I started taking Exjade 1500 mg daily in January 2006. Hurray!!!! This was another blessing. Every morning I dissolve the Exjade tablets in water and drink it. I've been on Exjade ever since except for 6 months when the Ferritin level went low enough (312) for me to come off. The dosages have varied over the last 7 years. I am currently taking 1,000 mg a day.

In September 2004, Dr. Alan List of the Moffitt Cancer Research Center stopped the Procrit injections so my system would be clean to start the CC5013 (Revlimid)

drug trial. My diagnosis was MDS subtype Refractory Anemia with Ringed Sideroblasts or RARS. The drug did not work for me. It did work for patients with 5q- chromosome malfunction. Results for these patients were amazing. Most of the patients with the 5q- had a significant reduction in their transfusion needs; some no longer needed transfusions at all. Half way through the trial I had a sense it wasn't working for me, but I went ahead and completed the trial because I knew the research collected from me might benefit other MDS patients later on.

During these past 15 years I have had 7 bone marrow biopsies. MDS is classified as high- or low-risk. I am in the low-risk category and my biopsies have not changed during these 15 years.

During my first 3 years I could not find any non-MDS specialists who knew anything about the disease. Also during this time there wasn't much or any research on MDS. The first research that took place was for high-risk patients. I totally agree with this because they are at greater risk to come down with leukemia. There is now research taking place for high- and low-risk patients. The good news is there are 100+ MDS research centers worldwide.

When I was first diagnosed with anemia, and then with MDS, I was in denial. This went on for 1 ½ years. As time went on I realized not many people knew about this disease so I decided to find out all I could and I began to keep detailed records of what was going on. I knew my body was the temple of the Lord, and I had a responsibility to take care of it. This is when my denial shifted to a positive attitude. I started by reading everything I could, looking up on the internet, talking to my doctor, and attending the MDS patient forums put on by the MDS Foundation. In fact, I continue to try to attend one or two a year. These forums have been very educational; we hear from doctors and nurses in the field, and from patients who share their experiences, ask and discuss questions.

I have also done several videos for the drug manufacturer of Exjade. This involvement has caused me to realize how much I appreciate what was taking place to find better ways to deal with iron overload.

I joined the “National MDS Registry” in June 2008. This is a registry that collects detailed information on MDS patients nationwide. Their goal is to help MDS patients by determining what the similarities and differences are in patients (what works and what doesn’t work).

Besides learning all I can about MDS from multiple avenues and getting involved, I have also used my faith to pray for and encourage other patients. Each time I get out of my vehicle to enter the Oncology Center or Infusion Center, I pray the Lord will put someone in my path that He wants me to speak to, encourage, or pray for. He honors this request each time. I also thank the nurses who attend to me and if they need to pray, I pray with them. When I go to the blood bank, I introduce myself to the donors and thank them for keeping me alive.

I believe this involvement is what is keeping me going. My positive attitude and faith have been strengthened every day.

To summarize, I would say, learn all you can about MDS, stay up to date on the research, stay positive, be motivated, and get involved—especially in patient forums. Ask questions of your doctor and nurses, and most of all keep God as your pilot.

Yes, it is true I have not been healed physically, but God has healed me spiritually, and my spirit is what will live on for eternity. I thank the MDS Foundation for allowing me to share this time with you. May God bless you now and forever.

I started by reading everything I could, looking up on the internet, talking to my doctor, and attending the MDS patient forums put on by the MDS Foundation.

MDS FOUNDATION

Stay Connected...

FOLLOW US ON:



GET INVOLVED!

Join the MDSF Development Committee!

The MDS Foundation is seeking members to join our Development Committee. Whether your contribution is time, skills, funds, or ideas you can make a difference!

For more information please contact Tracey Iraca at tiraca@mds-foundation.org or call **800.637.0839**.

SUPPORT THE MDSF!

Please make a tax-deductible donation today. Kindly use the enclosed donation envelope or go to www.mds-foundation.org to make your donation.



Please think of the MDS Foundation in your holiday giving this year and help people **LIVING** with MDS.
THANK YOU FOR YOUR CONTINUED SUPPORT!



SIGN UP TO VOLUNTEER!

If you are interested in helping out in the MDS Foundation office or in attending events as a representative of the MDSF, please call us at **800-MDS(637)-0839**.

LIVING ENDOWMENTS

Living Endowment Donations Have Been Made in Honor of:

Edwin Goldberg

These donations were submitted by: Lucille B. Gerber, Marlton, NJ • Irwin and Regina Friedman, Marlton, NJ • Edith Graczyk, Marlton, NJ • Arleen Cohen, Marlton, NJ • Nelson and Barbara Weisberg, Marlton, NJ • David and Marilyn Staiman, Marlton, NJ • Patricia Shelfer, Marlton, NJ • Joyce Burnstein, Marlton, NJ • Jerald and Jean Campenella, Marlton, NJ • Mark and Doris Gendelman, Marlton, NJ • E.M and N.R. Debs, Marlton, NJ • Fred and Shelly Weiner, Marlton, NJ • Toby Necky, Marlton, NJ • Leonard and Rona Egan, Marlton, NJ • Marcello and Celestine DiPietro, Marlton, NJ

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Baking for MDS

Audrie Lawless

Babycakes Project

My mother is the most beautiful woman in the world (maybe I am biased)... There are plenty of things in this world to support that statement, however. She's the type of woman that goes a thousand miles beyond 'out of the way' to help people – whether it's caring for her sick Dad, working one of her two jobs, tending to my brothers and I, or simply being there for a friend or a good laugh. She does everything with grace and never expects anything but love in return.

It's been two years since my mother was diagnosed as having MDS. The first few months were devastating. I watched as she scrambled around trying to find doctors and second opinions. I tried to assist in finding options for help if she needed to go into treatment and couldn't continue working. Watched as close friends and family offered to help with my little brother, finances, doctor's appointments, and anything else she could possibly need. This strong, brave woman that never asked for help from anyone had to accept that she may, in fact, need to rely on someone else for nearly everything. Having one son in the military, one only ten years old, and me, she was still trying to make it seem like everything was and would be just fine. So far, she's been doing alright. She has days where she barely makes it through the day without feeling entirely defeated – but she still fights on.

We've been lucky in that they caught this early. For now, she has declined the stem cell study and chemotherapy she was offered for fear of it making her sicker. She fights on each day, she smiles, she laughs and she makes sure that everyone is taken care of. This started to drive me crazy! I felt helpless. She didn't need anything, didn't want sympathy, and didn't need help – just love (typical Mom).

After much thought, and realizing at this point there is nothing I can do for her other than support her, I mixed my inner need to do something with my talent of baking and whipped up something delicious. February 5, 2013, was the official 'launch' of my *Babycake's Project*. What I do is bake delicious and adorable treats, sell them, take only what I used in supplies, and donate the rest to MDS Foundation. In the first month, I did a very soft and quiet launch. I kept it very small because I can only handle so many orders at a time as I do have a full time job too. To date, I've had 9 orders, as well as holding a bake sale at my job. I was amazed, excited, grateful and so optimistic that the first month went this well. I only have good vibes about what the future holds (for my Momma and the baking)!

I hope that in reading this you find strength and inspiration. Know that the

knowledge and awareness of MDS is being delivered to many via cupcakes and cookies, and that with every milestone and person we encounter we are supporting those fighting MDS, and taking one step closer to finding a cure for this disease!



Know that the knowledge and awareness of MDS is being delivered to many via cupcakes and cookies, and that with every milestone and person we encounter we are supporting those fighting MDS...



A Spouse's Story

Janet Pearson

My husband William has MDS.

The initial diagnosis was 10 years ago (the internet description and prognosis of MDS was more frightening than hopeful). In 2002, William was in Poland for two weeks and on his return he saw his family doctor. The blood work from that visit showed hemoglobin of 88 mg dL (8.8 g/dL). He was then referred to a hematologist.

A bone marrow aspiration was done in January 2003. William's hemoglobin at that time was 81 mg/dL (8.1 g/dL). We spoke with the hematologist about a bone marrow transplant, but his age was a concern.

The doctor put William on a drug which maintained his hemoglobin counts, and sustained our quality of life for about 4½ years.

Our lives carried on as if nothing was threatening our longevity together. We played golf together, vacationed, and socialized. William travelled to Europe on business trips, and his life was visibly unaltered. I was working, playing piano, painting, going to yoga and enjoying the daily activities that were a part of a relaxing lifestyle.

In April of 2007, our lives were altered with a 4:00 am hospital visit. William's hemoglobin was 80 mg/dL, which meant another bone marrow aspiration, transfusions, and other diagnostic testing to check for a possible source of bleeding.

Diagnostic tests proved normal. The bone marrow confirmed MDS had evolved to a more critical level, a more aggressive treatment would be required. Transfusions continued every two weeks. An appointment was arranged at a major cancer centre in September of 2007. This initial appointment required another bone marrow test, and weekly appointments which were then followed by biweekly appointments. These bone marrow results confirmed that this type of MDS did not fit the criteria for



any of the drug trials that were currently in place. This information was expressed to us at one of our October meetings. The hematologist at that time talked about Cyclosporine being an option; however, it would require approval from the government for insurance coverage. Treatment was approved and William began the medication in January 2008. The side effects were frightening.

This was a very difficult time for me. I would call home from work several times a day to check on him. If he didn't answer the phone, I would call my neighbor so that she could reassure me, and let me know that he was okay. Often times she would find him asleep in his chair in the yard. He was so pale that she would check to see if he was breathing. She would call his name to stir him awake. Everyone noticed a difference in William.

When William had iron overload I spoke with a dietician and asked about diet and foods to avoid. Tea was recommended, and if eating red meat always have a glass of cab-sauvignon wine, not Merlot, not Shiraz, but cabernet sauvignon. When Williams hemoglobin reached 140 (14.0) I thought of phlebotomy and shared this with him and the hematologist. He had three phlebotomy sessions to help remove the excess iron. I also believe in the importance of getting out for maybe (3) 10 minute walks a day—keep moving. When his creatinine started creeping up, drinking more water was important. I still bug him about drinking water.

I am not here to tell his story but that's what I find I am doing. MDS has consumed so much of me. How has it affected me? I work, I worry. Fear sometimes consumes me. Fear of being alone, fear of what he has to go through, fear of the unknown. I know I cannot do anything about it. It is difficult to share this fear with others who do not understand MDS. You see, on the outside I project a well put together woman. I appear to be calm, but my insides are continually racing. I have been told that I am a patient and kind person, and I care so much.

I feel that I have been compromised out of fear. We used to walk for miles, chatting and laughing. Walking at a good pace, and in all kinds of weather, be it sun, rain or snow. We would sit out on summer evenings, but West Nile Virus has precipitated a fear in us. Walking is now a slow to medium pace. Distance, depending on the day, may be very short. One Sunday evening William initiated a walk, he said, "Let's go down to the lake." We walked for 2 kilometers. It was a beautiful evening. The following night however was different. Walking any distance was impossible, he was sure it was from the walk the night before; so you see I grab and hold on to these impulsive and special moments.

How has it affected me?
Fear sometimes consumes me. Fear of being alone, fear of what he has to go through, fear of the unknown. I know I cannot do anything about it...
You see, on the outside I project a well put together woman. I appear to be calm, but my insides are continually racing...

FAMILY STORIES

Last year in September, (this is usually when we vacation), we did not travel. William had an old sports injury that flared up and restricted his mobility. Therefore, rest, ice and heat were in order. During that time I started walking with my neighbor from 7–8 am Monday to Friday for 3 weeks, it felt great. We are still walking on the days that I have off from work. This is my time.

I have written letters to William regarding my fears and my frustration, but have never shared them with him.

I love my life with William; I grab the moments that we share together. The little

things like cooking together, shopping, short walks, and whatever vacation time we have.

My job is in the Intensive Care unit in an administrative position. Due to the fact that this is a high risk floor in the hospital, I feel the daily stresses that encompass the patients and their families also contribute to my fears.

With the fears, frustration and uncertainty, it is important to take care of yourself as a caregiver. Take time for yourself. I like to read, have lunches with friends, knit, walk and have started a quilt. I will be starting a yoga class in November with a friend.

With the fears, frustration and uncertainty, it is important to take care of yourself as a caregiver. Take time for yourself. I like to read, have lunches with friends, knit, walk and have started a quilt.

FAMILY STORY: RAISING AWARENESS

Bar Mitzvah Project Raises Awareness of MDS

Sheryl Billman, Plano, TX

As part of his bar mitzvah project, our son Joshua hosted a fundraiser walk on October 6th, 2013. Thirty of our closest friends turned out on a beautiful fall day for this event. The purpose of this project was to raise awareness of MDS and to honor the memory of his grandfather, Bill Weisberger (my father) who died May 4th of this year secondary to complications resulting from MDS.



MDS FUNDRAISING EVENTS

WORKING TOGETHER FOR MDS

Corks for a Cause – A Fundraiser to Benefit the MDS Foundation

Judy DeWeese
San Antonio, Texas

35 years ago I joined the National Association of Women in Construction (NAWIC) and I had the honor of serving as national president in 2011–2012. NAWIC is a national association with approximately 140 chapters throughout the US and international affiliates in several other countries. Our mission is to assist women in establishing and advancing their careers in all areas of construction.

In April 2012 (midway through my term as NAWIC President) I was diagnosed with Myelodysplastic Syndrome (MDS).

Misshapen blood cells were found on routine blood work and I was immediately referred to the Cancer Care Centers of South Texas (an MDS Center of Excellence)



and Dr. Sridhar Beeram. Because of the early diagnosis and the excellent care from Dr. Beeram and the CCST team, my schedule was hardly limited. (I did cancel two pre-planned trips that came early in the chemo treatment. I was too uncomfortable being in crowds at that stage.)

I made the decision to be very open about MDS and my treatment. Perhaps I can help someone else who faces this path as a patient or a caregiver. When I was diagnosed, I had never heard of Myelodysplastic Syndromes. Through several

web searches I came to the MDS Foundation and questions I did not know I had were answered. And, I continue to go back for additional information.

When the San Antonio, Texas Chapter of NAWIC asked if they could sponsor a fundraiser in my honor, my first thought for the beneficiary was the Foundation from whom I have gained so much knowledge.

On August 23rd the NAWIC Chapter sponsored Corks for a Cause; a wine taster with all the profits to benefit the MDS Foundation. We had 25–30 in attendance and raised \$1,000 (\$750 was raised that evening and an additional \$250 was made as a direct donation at MDS-foundation.org).

I know that our donation will be put to good use and it will help benefit others through research in MDS. Thank you to the staff at MDS Foundation for all you do for physicians, patients, and caregivers.

For information about NAWIC contact nawic.org. For information about MDS contact www.MDS-foundation.org.

6 Years of Golf Tournaments Raise More Than \$22,000

A special thank you to Paul Wenzel who held his 6th Annual Golf Tournament in memory of his beloved mother, Karen A. Wenzel, who passed away on June 19, 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.

**THANK YOU so much Paul –
and well done!**



**For years to come we will
continue to keep my
mother's memory in our
hearts and minds, and
continue to support the
MDS Foundation!**

Paul Wenzel

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Tampa, Florida, United States

Initiated in 2011, the MDS Foundation International Nurse Leadership Board (MDSF-NLB) continues to expand and provide an international nursing forum for the development of patient, caregiver and nursing focused initiatives that promote excellence in the comprehensive care of the patient with bone marrow disorders. Members of the MDSF-NLB are invited to participate based on demonstrated excellence in nursing practice and research related to patients with bone marrow disorders, including MDS. The MDSF-NLB represents various regions and practice settings throughout the world.

Being a member of the NLB has been an enlightening process, sharing with other professionals our joint experiences and knowledge has, I hope, led to an even greater depth which in turn can be passed on to my patients. The MDS patient/cancer experience can be scary and very daunting and I hope as much as we can to alleviate such worries.

Natalie Singer

To date this remarkable group has facilitated patient and caregiver forums in the United States and Europe; published a supplement in the Clinical Journal of Oncology Nursing; completed an MDS Nurse Mentorship Program including facilitation and presentation at 6 regional meetings; published a Mentorship Monograph; held educational nursing sessions in conjunction with the Oncology Nursing Society; developed and distributed nursing educational slide modules specifically designed for Europe; developed an innovative interactive patient and caregiver resource available through the MDS Foundation – Building Blocks of Hope®; developed an interprofessional educational program that includes live roundtable meetings, webinars, and an online clinical toolbox – The MDS Academy; and translated and adapted MDS

Foundation educational materials into multiple languages. This year alone board membership has expanded to include additional members in Australia, Germany and the USA; and new members in Singapore and Japan.

The single most influential component of my professional career has been the opportunity to serve and be an active part of the NLB. Through the collaboration with my fellow NLB members I've mentored and written an MDS article in a peer reviewed journal, and been involved in international efforts to increase knowledge of other nurses and patients! My favorite part of being an NLB member is leading the patient forums around the country and playing a small part in a patient/family journey with MDS. It is quite an honor to bring helpful, accurate information to this wonderful group of people.

Jean Ridgeway

It is my great pleasure working together with my colleagues in the NLB. It is extremely important to present on the 'Challenges of MDS' and to organize study days where physicians and nurses present on the latest developments and trends in the treatment of adult and paediatric patients with a Myelodysplastic syndrome. On October 11, 2013 we organised our first Patient Event in Switzerland, which showed how important it is that patients and their relatives are regularly informed about the new trends on MDS.

Erik Aerts

INFORMATION ON CLINICAL TRIALS

NATIONAL CANCER INSTITUTE TRIALS

New Research Protocol Listing

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

Access
www.clinicaltrials.gov
for additional information.

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

Announcing A New Clinical Trial

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.

Medical Education: Diagnosis and Prognostication of MDS



REGISTER

We would like to involve you in to the diagnostic work-up process and make you familiar with the interpretation of the results and discuss the variety of clinical, laboratory, morphologic and cytogenetic factors influencing or reflecting individual prognosis of MDS.

- Real-time scoring
- Direct interactive expert feedback
- Dozens of interactive cases
- Expert lectures

Free Access (after registration)
www.MDSDIAGNOSIS.COM

COURSES

In-depth training on specific scoring techniques.

Patient profile based training covering the diagnostic value of each additional technique to an individual case.



LECTURES

Learn about the basics and specifics of each relevant MDS biomarker scoring technique by viewing our 15 minute expert lectures.



SCIENTIFIC COMMITTEE

Provided by global leading MDS experts:

Dr. Ulrich Germing
Dr. John Bennett
Dr. Detlef Haase
Dr. Arjan van de Loosdrecht
Dr. Raphael Itzykson
Dr. Leonie Saft
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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

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

Scottsdale, Arizona

Raoul Tibes, MD, PhD

The University of Arizona Cancer Center

Tucson, Arizona

Ravi Krishnadasan, MD, FACP

CALIFORNIA

Cedars-Sinai Medical Center

UCLA School of Medicine

Los Angeles, California

H. Phillip Koefler, MD

City of Hope National Medical Center

Duarte, California

Stephen J. Forman, MD

Moore's Cancer Center at the

University of California, San Diego

Rafael Bejar, MD, PhD

Peter Curtin, 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

James M. Foran, MD

Alvaro Moreno-Aspitia, MD

Sylvester Comprehensive Cancer Center

University of Miami

Miller School of Medicine

Miami, Florida

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Alan F. List, MD

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School of Medicine

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Amelia Langston, MD

The Blood and Marrow Transplant Program at Northside Hospital

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Asad Bashey, MD

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Minneapolis, Minnesota

Erica D. Warlick, MD

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School of Medicine

Siteman Cancer Center

St. Louis, Missouri

John F. DiPersio, MD, PhD

NEBRASKA

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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

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Columbia University Medical Center

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Icahn School of Medicine at Mount Sinai

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Campinas, Brazil
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Universidade Federal de São Paulo
São Paulo, Brazil
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Toronto Sunnybrook Regional Cancer Centre
Toronto, Ontario, Canada
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University of Toronto Hospital for Sick Children
Toronto, Ontario, Canada
Yigal Dror, MD

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Tianjin, China
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The Sixth Hospital Affiliated to Shanghai Jiaotong University
Shanghai, China
Xiao Li, MD, PhD

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Kyoto, Japan
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for Blood Disorders**

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Transplantation Center

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Laboratorio del Citologia-Citogenetica

Barcelona, Spain
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Karolinska University Hospital Huddinge

Stockholm, Sweden
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University Hospital Zurich

Zurich, Switzerland
Bernhard Gerber, MD

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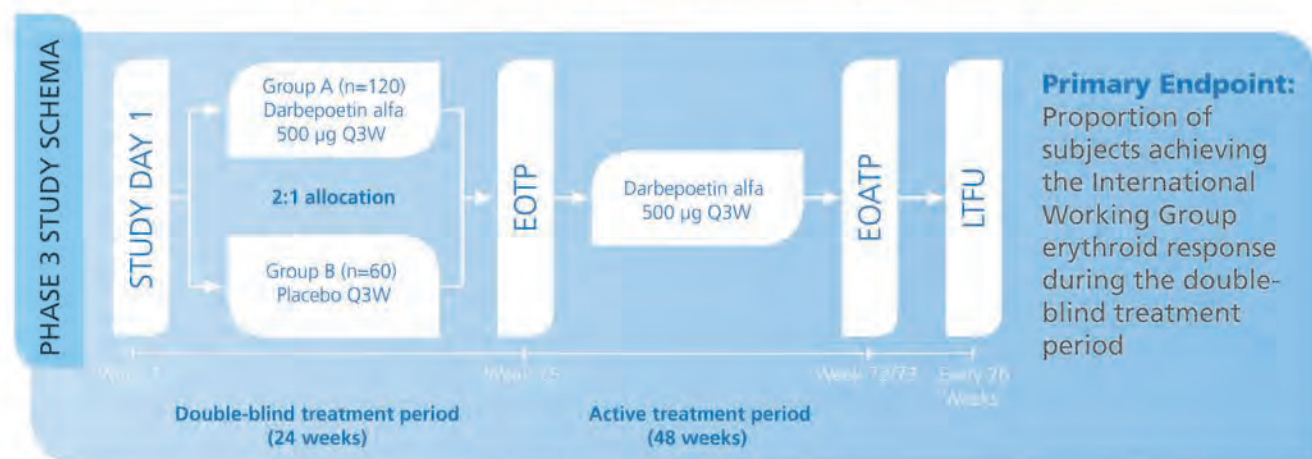


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A Multicenter, **R**andomised, Double-blind, Placebo-**C**ontrolled Study of Darbepoetin **A**lfa for the Treatment of Anaemic Subjects With Low or Interme**D**iate-1 Risk My**E**lodysplastic Syndrome (MDS)



LTFU contacts occur every 26 weeks following EOATP for a minimum of 3 years from first dose of IP

KEY INCLUSION CRITERIA

- ✓ Age ≥ 18 years with low or intermediate-1 risk (IPSS) MDS
- ✓ WHO classification of RA, RARS, RCMD, MDS-U, MDS with isolated del(5q), RAEB-1
- ✓ Hb ≤ 10 g/dL
- ✓ ECOG PS = 0 or 1

KEY EXCLUSION CRITERIA

- ✗ Evidence of bone marrow collagen fibrosis
- ✗ High transfusion demand (≥ 4 units of RBC transfusion during either of 2 consecutive 8-week periods prior to randomisation)
- ✗ Previous or ongoing use of ESA therapy
- ✗ Previous or planned use of biologic response modifiers to treat MDS during double-blind treatment period

For information on study participation and recruitment, go to www.amgenoncology.com for your local Amgen Medical Information Contact

ECOG PS – Eastern Cooperative Oncology Group Performance Score; EOATP – End of Active Treatment Period; EOTP – End of Treatment Period; IPSS – International Prognostic Scoring System; LTFU – Long-term Follow-up; Q3W – dosing every 3 weeks; WHO – World Health Organisation

Darbepoetin alfa is not approved for the use in patients with myelodysplastic syndromes (MDS) by the FDA, EMA and other local regulatory authorities. This information should not be construed as a recommendation for use of any product for unapproved uses.

AMGEN

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CLARITY

A Three-Year MDS Observational Study

Clinical Evaluation of Next Generation Sequencing (NGS) for the Diagnosis and Management of Myelodysplastic Syndrome (MDS)

Genoptix is researching the role of a number of gene mutations in patients with MDS using an Investigational Test. This clinical study is an evidence-driven approach that aims to improve physicians' abilities to diagnose and manage patients more effectively.

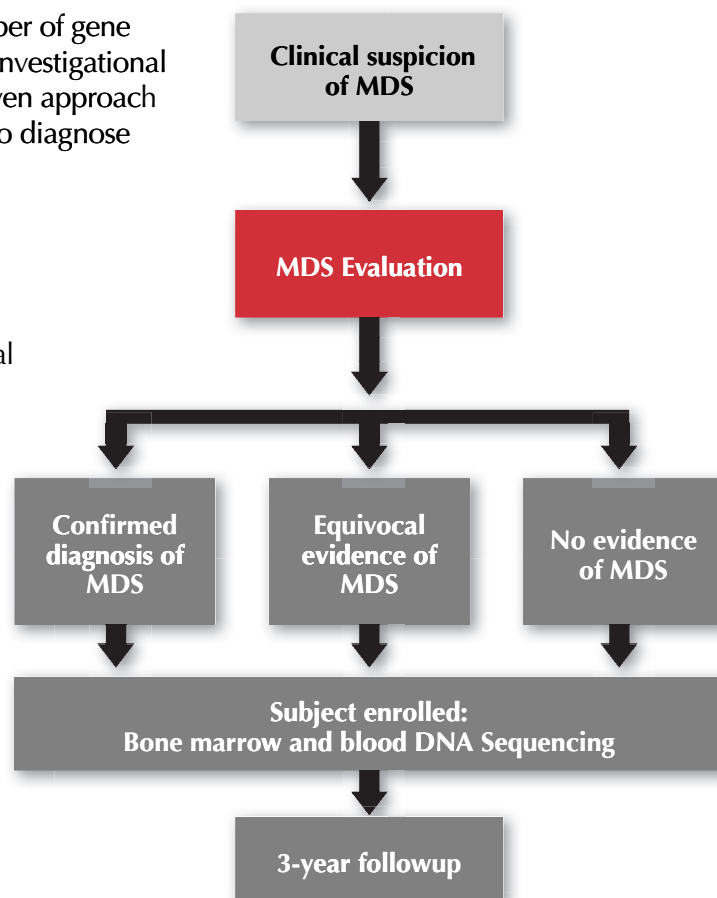
Study Requirements:

- ☐ Clinical suspicion of MDS
- ☐ Available bone marrow for Investigational Test and additional central laboratory diagnostic evaluation
- ☐ Patients would not be eligible if they have a current diagnosis of hematopoietic malignancy

Note: Concomitant patient enrollment in other studies is permitted.

Physicians – you could be an Investigator if:

- ☐ Your site supports clinical trials
- ☐ Your site sees at least 2 suspected MDS patients per month



To learn more about this MDS study,
contact: clarity@genoptix.com

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