



MDS NEWS HIGHLIGHTS

FROM THE GUEST EDITOR'S DESK

■ Transfusion Dependence and Transfusion Support in MDS: Current Guidelines for Transfusion

Presented by *Sandra E. Kurtin, RN, MD, AOCN, ANP-C*
The University of Arizona Cancer Center



PLAN TO ATTEND OUR FUTURE SYMPOSIA

ASH 2014 MDS FOUNDATION BREAKFAST SYMPOSIUM

December 5, 2014
 San Francisco, California



13TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES

April 29 – May 2, 2015
 Washington, DC



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FROM THE GUEST EDITOR'S DESK

GUEST EDITORIAL

Transfusion Dependence and Transfusion Support in MDS: Current Guidelines for Transfusion



Sandra E. Kurtin, RN, MS, AOCN,
ANP-C

The University of Arizona
Cancer Center

Transfusion Dependence in MDS

Transfusion dependence (TD) in MDS is inevitable. More than 90% of patients diagnosed with MDS will require packed red blood cell transfusions over the course of their disease due to disease related abnormal erythropoiesis, a hallmark finding in the diagnosis of MDS. The presence of anemia is often the first presenting symptom for patients with MDS. Both the Revised International Prognostic Scoring System (IPSS-R), and the World Health Prognostic Scoring System (WPSS), include either anemia or TD in the risk analysis of the disease (Greenberg et al., 2012; Malcovati et al., 2007). Additionally, transfusion dependence is often considered a trigger to consider initiation of disease modifying therapy, and transfusion independence is a common clinical trial endpoint for disease modifying therapies (Kurtin, 2013). Furthermore, transfusion independence has been found to correlate with improved quality of life (Szende, et al., 2009). It is not in the scope of this column to provide a comprehensive review of transfusion practices and the consequences of transfusion on MDS. This brief column serves to highlight some of the recent relevant publications, organizational guidelines, and patient-related outcomes associated with transfusion dependence in patients with MDS.

The Impact of Transfusion Dependence in MDS

Platzbecker and colleagues conducted a literature review summarizing published data relevant to clinical, quality of life and economic consequences of anemia and transfusion dependence in patients with MDS (Platzbecker et al., 2012). Of the 2678 unique citations, only 46 articles met the stringent criteria for inclusion in this review. Several key findings relevant to transfusion dependence in MDS were identified including: 1) a negative impact on overall survival and leukemia free survival; 2) an increased risk of infections; 3) an increased risk of transfusional hemosiderosis (iron-overload) with associated increased morbidity and mortality; 4) inferior quality of life; 5) increased costs of care; 6) and increased symptom burden of MDS (Platzbecker et al., 2012—see complete references in article). A population-based evaluation of 3149 incident cases of hospitalized patients with MDS in Australia between 1998 to 2008, found an increased incidence of congestive heart failure (IRR, 1.92; 95% CI, 1.41–2.60), bacterial (IRR, 1.75; 95% CI, 1.37–2.24) and fungal infections (IRR, 3.13; 95% CI, 1.70–5.75) and leukemia (relative risk [RR], 1.42; 95% CI, 1.07–1.88) and sepsis as cause of death (RR, 1.23; 95% CI, 1.03–1.47) (McQuilten et al., 2014). Given these findings, it is imperative to individualize transfusion support for patients with MDS based on established guidelines for transfusion.

Transfusion Guidelines

In December 2013, the American Society of Hematology (ASH) released a campaign called “Choosing Wisely”. This campaign was initiated in collaboration with The American Board of Internal Medicine (ABIM) Foundation, a non-profit organization focused on improved quality of care and professionalism (Hicks et al., 2013). The ASH Choosing Wisely Task

Force was convened in 2012 to begin to evaluate common practice patterns that based on current evidence could be improved to reduce potential harm, reduce costs, and improve the quality of care for hematology patients (Hicks et al., 2013). Five final items were selected, validated by experts and ASH members, and released to the membership in December, 2013 (**Table 1**). Among the five focus areas was the recommendation to transfuse the smallest effective dose of packed red blood cells (PRBC) to alleviate symptoms. This recommendation is based on a number of studies of hospitalized patients that show liberal transfusion strategies are not only more costly, but do not improve patient outcomes, and can in fact, place the patient at risk for potential harm (Carson et al., 2012; Napolitano et al., 2009; Retter et al., 2013; Rodgers et al., 2012; <http://www.sanquin.nl/en/productsservices/bloodproducts/transfusionguideline/>; <http://www.topalbertadoctors.org/cpgs.php>).

Table 1. American Society of Hematology Choosing Wisely Campaign: 2013

1. Use the minimum number of red blood cell transfusion units to treat symptoms of anemia or to return a patient to a safe hemoglobin range
2. Do not test for thrombophilia in adult patients with venous thromboembolism occurring in the setting of major transient risk factors
3. Do not use inferior vena cava filters routinely in patients with acute venous thromboembolism
4. Do not administer plasma or prothrombin complex concentrates for non-emergent reversal of vitamin K antagonists
5. Limit surveillance CT scans in asymptomatic patients after curative-intent treatment for aggressive lymphoma

The recommendations are based on several international organizational guidelines including the American Society of Anesthesiologists task force, the British Committee for Standards in Haematology, the Australian and New Zealand Society of Blood Transfusion, Society of Critical Care Medicine, the Italian Society of Transfusion Medicine and Immunohaematology, and the American Association of Blood Banks. The majority of the guidelines are based on data obtained from hospitalized patients, many of whom were in the intensive care unit during their hospital stay or had undergone major surgery (Hicks et al., 2013). In these populations, restrictive transfusion practices did not change patient outcomes. However, there are few trials that directly evaluate the use of restrictive transfusion practices in ambulatory oncology patients, in particular, patients with underlying bone marrow cancers.

The primary rationale for RBC transfusion in patients with Myelodysplastic Syndromes (MDS) is to improve the symptoms and reduce the risk associated with chronic anemia. The benefits of transfused blood are temporary, and in patients with repeated transfusions may become less apparent over time. There are a number of risks associated with RBC transfusions, the most common being non-hemolytic transfusion reactions. More serious, and even potentially life-threatening reactions are rare, but should also be considered when evaluating when to transfuse and how many units of RBCs should be given (**Table 2**).

In general, the hemoglobin (Hgb) level alone should not be the sole factor guiding the decision to transfuse. However, as illustrated in Table 1, transfusion is recommended for a Hgb <7g/dL and should rarely be administered for a Hgb>10 g/dL (Hicks et al., 2013). Transfusion for Hgb <8g/dL in ambulatory settings is fairly common, but has not been studied. There are a number of considerations for patients with Hgb in the range between 6g/dL and 10g/dL, including comorbidities, age, percentage and rate of the drop in Hgb, and various

Table 2. Benefits and Risks Associated with Red Blood Cell Transfusions

Benefits

- Rapid increase in Hgb may improve fatigue in some patients – although temporary if underlying causes are not addressed.

Risks

- Viral transmission: HIV: 3.1/100,000, hepatitis C: 5.1/100,000, hepatitis B: 3.41–3.43/100,000
- Transfusion-related acute lung injury (TRALI): 0.81/100,000
- Transfusion-associated circulatory overload (TACO): 1%–6%, higher in ICU and postoperative settings
- Fatal hemolysis: 1.3–1.7/million transfused units
- Febrile nonhemolytic reactions: 1.1%–2.15%
- Hemosiderosis (iron overload) – get stats

Table 3. Transfusion Guidelines

1. Requires informed consent for potential risks and benefits
2. Each unit of PRBCs should raise the Hgb by 1 gm/dL
3. Transfuse the minimum number of units needed to improve symptoms
4. Asymptomatic patients: transfuse to maintain Hgb 7–9 g/dL
5. Symptomatic with hemorrhage: transfuse to maintain hemodynamic stability
6. Symptomatic with Hgb <10 g/dL: transfuse to maintain Hgb 8–10 g/dL
7. Acute coronary syndromes with anemia: transfuse to maintain Hgb >10 g/dL
8. Consider individual patient attributes:
 - a. Co-morbidities, in particular cardiovascular disease or recent myocardial infarction
 - b. Amount and rate of blood loss
 - c. Additional recommendations for patient in the critical care or emergent care settings assuming the patient is normovolemic and anemia is the probable cause:
 - i. Mean arterial pressure <60 mmHg (or <70–80% of baseline), heart rate >110–130 pulse/min (or >120–130% of baseline).
 - ii. New ST-segment depression or elevation of at least 0.1 mV in an electrocardiogram
 - iii. New wall motion abnormality in trans-esophageal or trans-thoracic echocardiography
 - iv. Mixed venous oxygen partial pressure <32 mm Hg, oxygen extraction ratio >40%,
 - v. Mixed venous oxygen saturation <60%, or >10% decrease in VO₂.

physiological triggers (**Table 3**) (Carson et al., 2012). Each unit of RBCs brings the Hgb up by approximately 1 gram. Although administering two units of RBCs is a common practice, the current guidelines suggest transfusion of 1 unit of RBCs if this will bring the Hgb to a level to alleviate symptoms.

Cost

Until these recent guidelines were issued, administering two units of PRBCs at each visit was the most common practice

for transfusion support (Hicks, et al., 2013). The process for determining if a patient needs a transfusion (evaluation of the CBC and patient symptoms), ordering the blood (type and cross match), and transfusing the blood may require several days depending on the setting. Once ordered, administering the blood requires a visit to the clinic or transfusion center with an average of 200 minutes per unit of blood from check-in to completion of the transfusion (Reitan et al., 2013). A retrospective chart review of 120

patients visiting a single transfusion center in the US estimated the labor cost of transfusion (in 2011 \$US) to range from \$46.13–\$49.33 per PRBC unit. The estimated fully loaded bundled cost was \$596.49 for transfusion of one unit of PRBC (Reitan et al., 2013). For patients who are transfusion dependent, the time required to prepare for and receive these transfusions can impose significant cost in terms of time and expenses.

Fatigue, Anemia and Quality of Life with Transfusion Dependence

Evaluation of 280 higher-risk MDS patients found that female gender ($P=0.018$), poor performance status ($P<0.001$), and lower Hgb ($P=0.026$) were independently associated with increased fatigue (Efficace, et al., 2014). Fatigue in turn, was most often associated with increased symptom burden. Quality of life in this analysis was more closely related to patient reported fatigue than was the degree of anemia. Pre-treatment fatigue has been reported to be associated with shorter survival time (Deschler et al., 2013). Thus, transfusion of PRBCs in MDS patients with TD anemia, may not be the best option to alleviate symptoms of fatigue.

Conclusions

Transfusion dependence is common in patients with MDS. Familiarity with the risk and benefits of transfusion, cost, quality of life and alternative treatments will provide patients and health care providers with a platform for discussing the role of transfusion support in individual patients. Clinical trials specific to patients with MDS are needed to further clarify the application of restrictive transfusion practices in this patient population. Thus, transfusion of PRBCs in MDS patients with TD anemia, may not be the best option to alleviate symptoms of fatigue. Rather, evaluating and treating the symptom burden associated with MDS as well as any comorbid conditions together with a general program for diet, nutrition and activity, may provide a better clinical approach to addressing fatigue and quality of life.

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FROM THE FOUNDATION

INTERNATIONAL PROGNOSTIC SCORING

LATEST NEWS ON THE REVISED INTERNATIONAL PROGNOSTIC SCORING SYSTEM FOR MDS

The IWG-PM Molecular Project:

The International Working Group for Prognosis in MDS (IWG-PM) continues to remain proactive under the aegis of the MDS Foundation for working to provide combined data regarding critical clinical and molecular information of MDS patients. Following on from their generation of the Revised International Prognostic Scoring System (IPSS-R) by the coalescence of clinical data from over 7,000 primary untreated MDS patients (*Blood*. 120:2454, 2012) analyzed from institutions worldwide, the cooperative group is now focusing on obtaining molecular data from a similarly large cohort of MDS patients and combining them with their clinical outcome information in order to

determine the mutational landscape of these patients. The initial report describing analysis of combined datasets from the IWG-PM-Molecular Committee has demonstrated that TP53 mutation status divides MDS patients with complex karyotypes into distinct prognostic risk groups, with those carrying the mutation having poorer prognoses (Bejar, Papaemmanuil, Haferlach et al, Proc ASH 2014). In addition, with ongoing studies of the group, generation of further data regarding potential molecular driver mutations for this spectrum of diseases is anticipated to provide useful targets for the future treatment of MDS patients.

The global project is being coordinated by Ben Ebert and Peter Greenberg (co-Chairs), Rafael Bejar and Ellie Papaemmanuil, with statistical support by Donna Neuberg, Kristin Stevenson and Heinz Tuechler.

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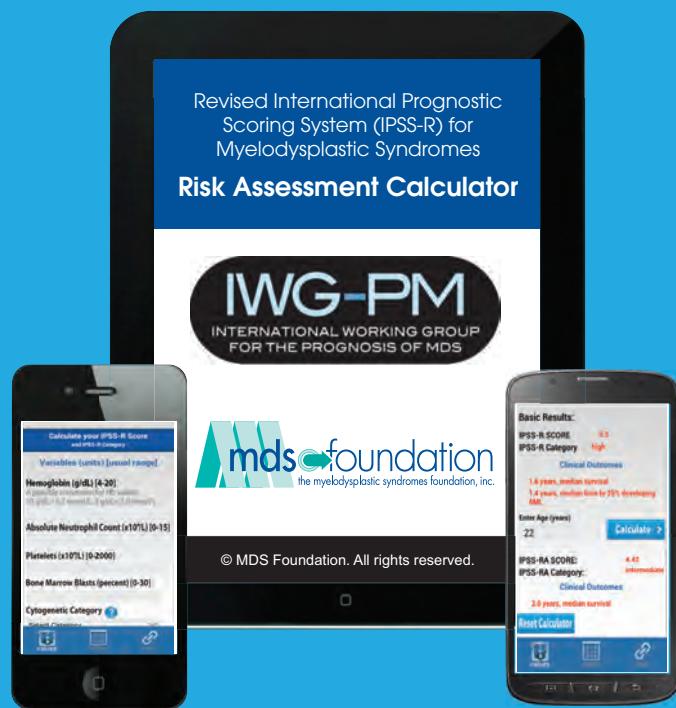
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IWG-PM

INTERNATIONAL WORKING GROUP
FOR THE PROGNOSIS OF MDS



MEETING HIGHLIGHTS AND ANNOUNCEMENTS

THE AMERICAN SOCIETY OF HEMATOLOGY 56TH ANNUAL MEETING & EXPOSITION • DECEMBER 2014

JOIN US FOR A BREAKFAST SYMPOSIUM

Current Therapeutic and Biologic Advances in MDS

DECEMBER 5, 2014

7:00 to 11:00 am

**The Moscone Center, San Francisco, California
West Building, Room: 2014/2016**

Breakfast will be served from 7:00 to 7:30 am.

TARGET AUDIENCE

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

LEARNING OBJECTIVES

- Describe the clinical and biologic features which are useful for classifying MDS and aid in therapeutic decision-making
- Explain the current modifications of epigenetic treatment options for MDS patients whose disease has not responded to standard therapy
- Describe newer conditioning regimens and alternative donor selections available for MDS patients
- Describe the impact of comorbidities and quality of life considerations in planning the treatment of MDS patients
- Identify the impact of microenvironmental immune-related abnormalities on hematopoiesis in MDS

FUNDING

This activity is jointly-provided by The Myelodysplastic Syndromes Foundation, Inc. and AKH Inc., Advancing Knowledge in Healthcare, Inc.

This activity is supported by an educational grant from Baxter Healthcare Corporation, Celgene Corporation, and Onconova Therapeutics, Inc.

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ACCREDITATION

CME/CE provided by AKH Inc., Advancing Knowledge in Healthcare.

Physicians: This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of AKH Inc., Advancing Knowledge in Healthcare and The Myelodysplastic Syndromes Foundation, Inc. AKH Inc., Advancing Knowledge in Healthcare is accredited by the ACCME to provide continuing medical education for physicians.

AKH Inc., Advancing Knowledge in Healthcare designates this live activity for a maximum of 3.5 AMA PRA Category 1 Credit(s)™. Physicians should claim only credit commensurate with the extent of their participation in the activity.

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Criteria for Success: Statements of credit will be awarded based on the participant's attendance, participation in the pre/post-test and submission of the activity evaluation form. A statement of credit will be available upon completion of an online evaluation/claimed credit form at www.akhcme.com/mds. You must participate in the entire activity to receive credit. There is no fee to participate in this activity. If you have questions about this CME/CE activity, please contact CME/CE provided by AKH Inc., Advancing Knowledge in Healthcare.



TO PRE-REGISTER:
<http://akhcme.com/MDS>

19TH CONGRESS EUROPEAN HEMATOLOGY ASSOCIATION

MILAN, ITALY ▪ JUNE 2014

The MDS Foundation was proud to once again attend the annual European Hematology Association Annual Congress held June 12–15 in Milan, Italy. Healthcare professionals from all across the world picked up their FREE copies of our MDS educational materials for themselves and their patients.



#EHA19 Sessions involving Patient Advocates from around the world building “real-world” connections. Patient advocates play a powerful role in the decision process. Shared connections can be a key point of influence to enhance communication and improve care.



THE MDS ALLIANCE

The MDS Foundation is proud to be a member of The MDS Alliance, a global coalition of patient groups, that believes that all MDS patients deserve the best multi-professional care regardless of age. Go to <http://www.mds-alliance.org> to learn more!



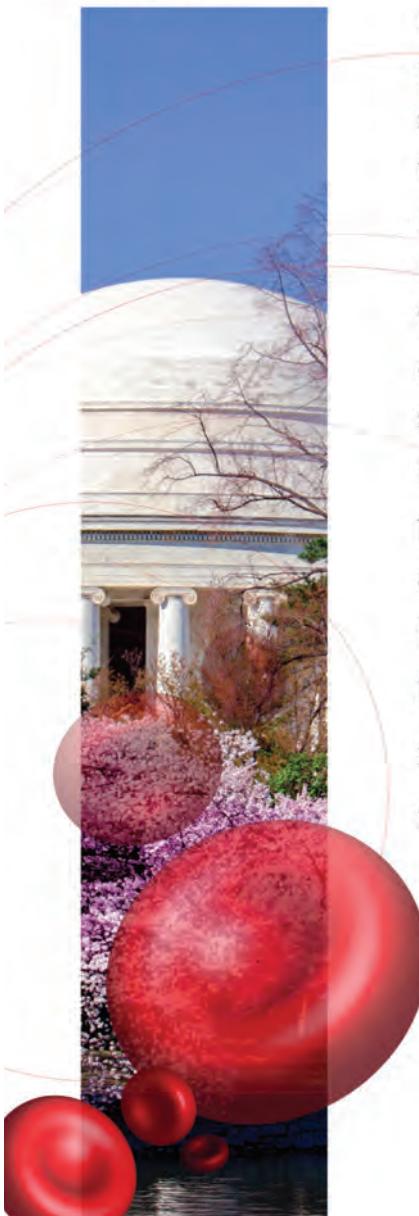
On behalf of the Scientific Committee and the MDS Foundation, I hope you will join us at the **13th International Symposium on Myelodysplastic Syndromes** taking place in Washington, DC from April 29 – May 2, 2015. The first return of this important meeting to the Western Hemisphere since 1993, we have initiated several changes which should make this an even more exciting venue to present and discuss the latest developments in MDS. Two simultaneous tracks will be available. The first, MDS Clinical State-of-the-Art will walk attendees through all clinically relevant aspects of MDS diagnosis, prognosis, and management. As usual, these talks will be given by international leaders, and will include panel discussions, point/counterpoint, and discussions of cases submitted by attendees. The second track, Next Gen MDS, will focus on the newest in MDS translational science. Each topic will have a plenary lecture delivered by an international thought leader, followed by research talks selected from the abstracts. We will of course continue to have poster sessions, Morphology workshops, and Nursing-focused seminars. In order for this program to succeed, we need the submission of abstracts based on your best work! Selection of abstracts will be competitive and will be performed by the Scientific Committee. We hope that this format will solidify this Symposium's role as the premier venue for MDS basic, translational and clinical research.

The Washington Marriott Wardman Park in Washington, DC is an outstanding venue and is conveniently located on the Metro Red Line. It is an easy walk to Dupont Circle and the White House. As usual there will be a wonderful dinner at a historic venue.

We look forward to seeing you in Washington!

Steven D. Gore

Symposium Chair



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Join us for MDS 2015 in Washington, D.C., USA, for this highly anticipated and multidisciplinary event which offers:

- » A high quality scientific program
- » Interactive discussions on the most recent achievements and discoveries in the field of hematology
- » Collaborative research opportunities
- » Networking with colleagues

PLENARY AND SYMPOSIA

TOPICS INCLUDE:

- » Biology of MDS Disease Progression
- » Epidemiology and Outcomes in MDS
- » Genomics and Epigenomics
- » Innate Immunity and bone marrow failure states
- » Management of Higher Risk MDS including transplant
- » Molecular Diagnostics
- » MDS: Preclinical and Mouse Models
- » MDS Microenvironment
- » Management of Lower Risk MDS
- » MDS and the Aging Stem Cell
- » MDS Predisposition
- » Overlap Syndromes including CMMoL
- » Prognostication
- » Splicing Factors
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REGISTRATION

Registration information is available online at www.mds.kenes.com. Group Registration procedure will be valid for a minimum of 10 participants and up.

HOTEL RESERVATIONS

As the official organizer of the Symposium, Kenes International is offering special reduced rates for various hotels in Washington. Visit www.mds.kenes.com.

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ABSTRACT SUBMISSION



ABSTRACT SUBMISSION FOR MDS 2015: NOW OPEN

ABSTRACT SUBMISSION DEADLINE: **WEDNESDAY, JANUARY 14, 2015**

Accepted abstracts submitted by **Wednesday, January 14, 2015** for the MDS 2015 Symposium will be published in the *Leukemia Research Journal* by Elsevier.

The Leukemia Research Journal is indexed in the following databases: Chemical Abstracts, Current Contents/Life Sciences; EMBASE; Elsevier BIOBASE; Medline; PubMed; Reference Update; Science Citation Index; Scopus

Participants who would like to present **oral and poster presentations** must submit an abstract for consideration by the **Scientific Program Committee**.

The presenting author is required to ensure that all co-authors are aware of the content of the abstract before submission to the Secretariat.

Abstracts accepted for presentation will be published on the website prior to the Symposium.

SUBMISSION

Abstracts should be submitted only via the online submission form.

RULES FOR SUBMISSION

- » An author from each abstract is expected to attend the Symposium and present the poster or oral presentation.
- » Previously presented abstracts will be reviewed however may be considered for poster presentation only.
- » All abstracts must be submitted and presented in clear English with accurate grammar and spelling of a quality suitable for publication. If you need help, please arrange for the review of your abstract by a colleague who is a native English speaker, by a university scientific publications office (or other similar facility) or by a copy editor, prior to submission.

GUIDELINES FOR SUBMISSION

Before you begin, please prepare the following information:

- Presenting author's contact details:
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- Full postal address
- Daytime and evening phone number
- » Presentation type – please choose from one of the following:
 - Poster presentation
 - Oral presentation
- » Author and co-authors' details:
 - Full first and family name(s)

- Affiliation details: department, institution / hospital, city, state (if relevant), country
- » Abstract title – limited to 25 words in Sentence Structure
- » Abstract text – limited to 400 words
- » (Please Note: Word count is affected when graphs/tables/images are added)
- » Abstract topic – abstracts must be allocated to a specific topic for the Scientific Program. Please choose from the list of topics below.
- » Tables – A maximum of 3 tables of up to 10 rows x 10 columns can be included per abstract
- » Graphs and images – It is important to note that each image included in the abstract is worth 30 words. A maximum of 3 images can be included per abstract.

TOPICS

- | | |
|------------------------|-----------------------------------|
| » Genetics | » Epidemiology of MDS |
| » Epigenetics | » Outcomes research |
| » Splicing Factors | » Microenvironment |
| » Preclinical Models | » Disease Progression |
| » MDS predisposition | » Clinical trials- non-transplant |
| » Immune dysregulation | » Clinical trials: transplant |
| » MDS stem cells | |

NETWORKING EVENTS

WEDNESDAY, APRIL 29, 4:30-6:45 PM, MARRIOT, HALL A

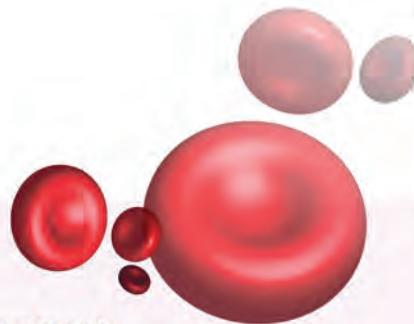
WEDNESDAY, APRIL 29, 7:00-9:30 PM, MARRIOT, EXHIBITION AREA **WELCOME RECEPTION AND MEET THE FACULTY**

FRIDAY, MAY 1, 7:30 PM, NATIONAL BUILDING MUSEUM

OPENING CEREMONY

WELCOME RECEPTION AND MEET THE FACULTY

NETWORKING DINNER



MDS PATIENT RESOURCES

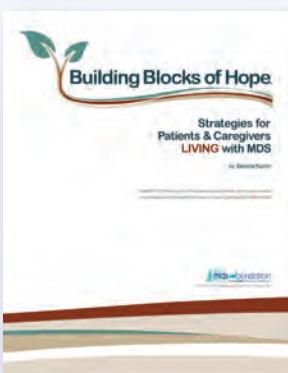
Translated Patient Resources Are Here!

The MDS Foundation is excited to be able to offer our patient and caregiver resources in several languages!!! Please use the links below to access these translations.

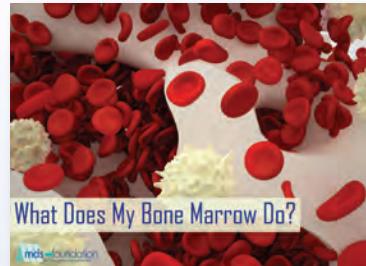
WHAT DOES MY BONE MARROW DO?

This booklet gives patients and caregivers general information on bone marrow function and how it is affected by MDS.

<http://www.mds-foundation.org/bone-marrow-handbook>



*Available in Dutch, Italian and Portuguese



BUILDING BLOCKS OF HOPE

This comprehensive resource contains information on MDS, available treatments and iron overload. It also gives MDS patients and their caregivers tools to take an active part in their MDS journey. Access this link to view an online version of the handbook, download a complete PDF of the handbook; and to view additional international versions of the handbook.

<http://www.mds-foundation.org/bboh/#International-Handbooks>

*Available in German, French Canadian, and English Canadian.
Translations in French and Spanish coming soon!

PRACTICE AND TREATMENT SURVEY

PLEASE TAKE OUR SURVEY...

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-PTSurvey>

PATIENT RESOURCES

Applying for Social Security Disability with Myelodysplastic Syndromes (MDS)

Lisa Giorgetti
Community Liaison
Social Security Disability Help

If you suffer from Myelodysplastic Syndromes (MDS), you may have difficulty working, as you need a range of medical treatments to prevent symptoms. MDS refers to a group of disorders related to the bone marrow, the diseases can affect your bone marrow as well as your blood and could lead to acute myeloid leukemia. If your life is impacted by MDS and prevents you from any substantial work activity, you may want to consider applying for Social Security Disability benefits.

Social Security Disability Programs

The Social Security Administration (SSA) operates two disability programs including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). To qualify for either program, you must meet the SSA's medical criteria as well as the technical criteria that are unique to each program. <http://www.disability-benefits-help.org/content/social-security-programs>

Social Security Disability Insurance (SSDI): SSDI is funded by the contributions made to the Federal Insurance Contribution Act (FICA). Hence, in order to qualify for the SSDI benefits, you need to have paid Social Security taxes for a certain number of years depending on your age. If you're 31 years or older, you should have paid these taxes for at least 5 years of the last 10 years. This basically means you need 20 work credits to your name to receive SSDI benefits. As of 2014, taxpayers earn one work credit for each \$1,200 that they earn, with a maximum of four work credits per year.

There are no asset or income limits to receive SSDI benefits and the sole basis for receiving the benefits depend on your medical condition, in this case MDS, and your past Social Security contributions.

Supplemental Security Income (SSI): If you don't have sufficient work credits to your name, you may be eligible to receive SSI benefits, as this is based on financial need rather than work history. All your assets should add to \$2,000 or less if you are single, excluding the home and one vehicle. If you are married, the couple's asset limitation increases to \$3,000. There are also income limitations, where you cannot make more than \$721 per month if you're single or \$1,082 per month if you're married.

Medical Eligibility Requirements

To qualify for either SSDI or SSI, you must prove to the SSA that you are disabled according to their criteria. Meeting a listing in the SSA's Blue Book, a publication containing all conditions that could qualify an individual for benefits, is the easiest way to be eligible. While MDS may not be listed in the Blue Book, there are other listings that could help to qualify an individual for benefits.

MDS is a group of bone marrow disorders, which can lead to a form of leukemia, and can be treated with allogeneic blood and marrow transplantation. Under Section 13.28 Malignant neoplastic diseases treated by bone marrow or stem cell transplantation of the Blue Book, an individual with MDS could qualify by:

- Undergoing allogeneic transplantation, which is considered a disability until at least 12 months from the date of the transplantation, or
- Enduring autologous transplantation, which is considered a disability until at least 12 months from the date of the first treatment under the treatment plan that includes transplantation.

In order to improve your chances of an approval of your SSDI or SSI application,

you will want to prove to the SSA, through medical evidence, that your MDS meets one of the conditions listed in the SSA's Blue Book publication. <http://www.disability-benefits-help.org/disabling-conditions>

Applying for Disability Benefits

When applying for Social Security Disability benefits, you can do so online or at your nearest Social Security office. Before applying, it's critical to gather as much medical evidence as possible to prove that your condition qualifies you according to a Blue Book listing or that your condition prevents you from performing any sort of work activity.

Throughout the application process, you will have to fill out several forms to apply for disability benefits. The forms and documents need to be filled out completely with as much detail as possible in order to show how your MDS affects your life. It can take anywhere from two to four months from the date of your application to receive a decision regarding your claim.

If you're awarded benefits, you will be notified as to what benefits you're entitled to, how much you will receive, and when your benefits will begin. If you're denied benefits, no need to worry because you have 60 days from the date of the denial to appeal the decision.

Many recipients are denied and go on to successfully get their benefits through the appeal process. If you intend appealing, you may want to work with a qualified and experienced disability attorney. The disability attorney will guide you through the appeal process and also present your case to the Disability Determination Services. These attorneys work on a contingency basis and their experience and knowledge can help improve your chances of being awarded benefits.

For further inquiries please contact Ram Meyyappan at Social Security Disability Help. Phone: 857-366-7629, Email: ram@ssd-help.org



MDS FOUNDATION PRESENTS FREE WEBINARS



MDS EPIDEMIOLOGY, PATHOPHYSIOLOGY, DIAGNOSIS, AND ASSIGNMENT OF RISK CATEGORY

Speaker: David Steensma, MD

Program Overview: This presentation reviews contemporary diagnosis and prognosis estimation for patients with myelodysplastic syndromes. The presenter discusses how newer molecular data including recurrent point mutations in genes encoding epigenetic regulators and splicing factors can be incorporated into MDS risk assessment.

Course Details:

ACCME: 0.50; ANCC: 0.50; ACPE: 0.50; Attendance: 0.50
Course opens: September 1, 2014, Course expires: Aug 31, 2015
Cost: \$0.00

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 the educational activity, participants should be able to:

- Apply symptom management strategies to maximize patient safety, quality of life, and adherence to the therapeutic regimen while minimizing complications due to disease process and treatments.
- Apply key principles necessary for optimal clinical management of the older adult including analysis of co-morbidities and criteria for safe and effective outpatient management.

Faculty: David Steensma, MD

Adult Leukemia Program
Dana-Farber Cancer Institute
Associate Professor of Medicine
Harvard Medical School
Boston, MA

Required Hardware/Software:

- A computer with an internet connection
- Internet Browser: Internet Explorer 7.x or higher, Firefox 4.x or higher, Safari 2.x or higher, or any other W3C standards compliant browser
- Other additional software may be required such as PowerPoint or Adobe Acrobat Reader

REGISTER: <http://akhcme.com/prognosis>



CURRENT PRACTICE STRATEGIES AND ONGOING CLINICAL TRIALS IN MANAGEMENT OF MYELODYSPLASTIC SYNDROMES

Speaker: Rami Komrokji, MD

Program Overview: Effective treatment of MDS requires an individualized, risk-adapted approach. Current strategies for the treatment of MDS, review of ongoing clinical trials and evolving agents for management of MDS will be discussed in this video.

Course Details:

ACCME: 1.00; ANCC: 1.00; ACPE: 1.00; Attendance: 1.00
Course opens: September 1, 2014, Course expires: Aug 31, 2015
Cost: \$0.00

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 the educational activity, participants should be able to:

- Interpret findings of key clinical trials that evaluated the use of FDA-approved and novel investigational agents
- Illustrate the pathobiology, clinical presentation, diagnostic evaluation and prognosis of myelodysplastic syndromes

Faculty: Rami Komrokji, MD

Clinical Director, Associate Professor
Department of Malignant Hematology
H. Lee Moffitt Cancer Center & Research Institute
Tampa, FL

Required Hardware/Software:

- A computer with an internet connection
- Internet Browser: Internet Explorer 7.x or higher, Firefox 4.x or higher, Safari 2.x or higher, or any other W3C standards compliant browser
- Other additional software may be required such as PowerPoint or Adobe Acrobat Reader

REGISTER: <http://akhcme.com/strategies>

Don't forget to access
the complete set of
tools on the MDS
Foundation website!



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Meet Your Board Members



INTRODUCING...

Nicole Crisp, RN, BScN, MN, NP-adult



Nicole Crisp

MDS Center of Excellence:

University of Alberta Hospital, Edmonton, Alberta, Canada

What led you to the nursing field? My father used to describe me as “the bleeding heart of the family”, referring to my caring concern for other people. I also had a passion for anatomy and was amazed at the intricacies of the human body. I was interested in how people’s physical, emotional, spiritual, and psychological well being impacted their health, so nursing seemed like an ideal career.

What interested you in hematology/myelodysplastic syndromes in general?

Hematology and myelodysplastic syndromes were interesting to me because they affect all ages, genders and types of people. It is not always obvious to an outsider that there is a problem, but when you review the patient’s blood work or bone marrow reports, you can understand why they feel the way they feel. I am challenged by new medications and treatment approaches that continually evolve; there is always something new to learn.

What is the most gratifying part of your job? The day to day contact I have with my patients. It is rewarding to know that even though they are in a difficult situation, I can try to make it more tolerable for them. This can be accomplished by providing emotional support, identifying an infection or bleeding issue and managing it, or by offering them improved access to care as a nurse practitioner, amongst other things. I learn so much from my patients about “what really matters”.



INTRODUCING...

Sara M. Tinsley, MS, ARNP, AOCN



Sara Tinsley

MDS Center of Excellence:

Moffitt Cancer Center and Research Institute, Tampa, Florida

Nursing Specialty: Oncology **Nursing School:** University of South Florida

Clinical Sites: Tampa General, Moffitt Cancer Center

Board Certification: Oncology Nursing Society, Advanced Oncology Certified Nurse

What led you to the medical field? I have a passion for helping people, and also educating individuals. Nursing was the marriage of my two passions.

What interested you in hematology/myelodysplastic syndromes in general? I first entered nursing taking care of a patient with acute myelogenous leukemia. I was encouraged by his brave fight with such a touch illness, which affected all aspects of his life. I enjoyed working with him through his treatment and eventual discharge home.

What is the most gratifying part of your job? I love the time spent with patients, during the good times, and the bad times. Relationships formed during patient encounters shaped my outlook on life.



INTRODUCING...

Núria Borràs-Maixenchs, RN



Núria Borràs-Maixenchs

MDS Center of Excellence:

Hospital Clinic de Barcelona, Spain

Medical Specialty: Hematology/Oncology nursing

Nursing School: Facultad de Medicina de la Universidad Central de Barcelona. Barcelona, Spain

What led you to the medical field? The diversity of people, tasks and situations to interact with.

What interested you in hematology/myelodysplastic syndromes in general?

Back in 1989–1991 working as a staff nurse at the Hematology out patient clinic MDS patients where the patients who did not come to get chemo”, they were depending on supportive care, mostly transfusions and that rose my attention and interest.

What is the most gratifying part of your job? Providing direct care to patients and families.



INTRODUCING...

Corien Eeltink

Corien M. Eeltink, RN, MA ANP



MDS Center of Excellence:

VU University Medical Center, Amsterdam, the Netherlands

Medical Specialty: Hematology

Medical School: Hanzehogeschool (Groningen)

Residency: Groningen, the Netherlands

Board Certification: Registered Nurse, Oncology Certification, Hematology Certification, Master of Arts Advanced Nursing Practice

What led you to the medical field?

The opportunity to contribute to improving high quality care by focusing on nursing interventions such as reducing distress, improving quality of life, and influencing certain geriatric aspects.

What interested you in hematology/myelodysplastic syndromes in general?

The complexity and the different features of the disease, and the impact this can have on daily living.

What is the most gratifying part of your job?

To stand by our patients and their near ones from diagnoses till end of life.



INTRODUCING...

Samantha Soggee

Samantha Soggee, RN



MDS Center of Excellence:

Leukaemia Foundation of Australia, Melbourne, Australia

Nursing Specialty: Myelodysplastic Syndromes and Myeloproliferative Neoplasms

Nursing School: La Trobe University

Board Certification: Australian Health Practitioner Registration Agency (APRAH)

What led you to the medical field?

I always had a passion for caring and was fortunate enough to fall into nursing – where I am able to care and advocate for people affected by haematological malignancies. I worked as an Oncology/Haematology Clinical Nurse Specialist in a major metropolitan hospital before commencing my role as National MDS/MPN Coordinator at the Leukaemia Foundation of Australia.

What interested you in hematology/myelodysplastic syndromes in general?

As a graduate nurse, I had a rotation in haematology and took an interest in the pathophysiology and treatment of the haematological malignancies. I had a deep respect for the patients and the health care team, who were admirable. The patients I looked after inspired me and lit a flame and passion for haematology nursing that continues to drive me. There was a lot of opportunity to learn about the more mainstream blood cancers, but I was always curious about the rarer diseases that didn't get as much focus, such as MDS.

What is the most gratifying part of your job?

The most gratifying part of my job is being able to instill a sense of hope, empowerment and control in the lives of the people I have been given the privilege to nurse and provide support services to, whose lives have been turned upside down by a diagnosis of a blood cancer.



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https://www.facebook.com/pages/MDS-Foundation-Inc/154245875037?ref=br_tf

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RN, MS, AOCN, ANP-C**

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United States

**Sara M. Tinsley,
ARNP, AOCN**
Tampa, Florida
United States

Catherine Vassili, RN
Victoria, Australia

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.ncbi.nlm.nih.gov.

EPIDEMIOLOGY AND OUTCOMES RESEARCH:

1. Prica A, Sholzberg M, and Buckstein R. Safety and efficacy of thrombopoietin-receptor agonists in myelodysplastic syndromes: a systemic review and meta-analysis of randomized controlled trials. *Br J Haematol.* 2014; Aug 26 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25155450>)

This meta-analysis of randomized placebo controlled trials included a total of 384 patients from five clinical studies (4 with romiplostim and 1 with eltrombopag). Overall, romiplostim was found to have a significantly lower risk of exposure-adjusted bleeding rates and platelet transfusion rates, both of which are important from patient perspective. However, apparently, the effect on leukemic progression could not be ascertained conclusively in this meta-analysis.

EPIDEMIOLOGY AND OUTCOMES RESEARCH:

1. Braulke F et al. Validation of cytogenetic risk groups according to international prognostic scoring systems by peripheral blood CD34+ FISH: Results from a German diagnostic study in comparison with an international control group. *Haematologica.* 2014 Oct 24 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/25344522>)

Bone marrow chromosomal banding information is missing in 5–20% of myelodysplastic syndrome cases. The present study in 328 such cases demonstrated feasibility of obtaining cytogenetic profile in peripheral blood CD34+ cells using fluorescence in situ hybridization technique and that, inclusion of this data in International Prognostic Scoring Systems (IPSS), yielded significant differences in overall survival and leukemia free survival.

TREATMENT:

Growth Factors:

1. Latagliata R et al. Erythropoietin treatment in patients with myelodysplastic syndromes and type 2 diabetes. *J Diabetes.* 2014; Jul 25 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/25060764>)

A high dose erythropoietin alfa treatment (2×40,000 IU s.c./week) was administered to 140 low risk MDS patients, of which 27 had concomitant type-2 diabetes. The erythroid response rates were comparable between diabetic (17/27 or 62.9%) and non-diabetic patients (62/113 or 54.8%, p=0.446). Neither did the two groups differ with respect to response duration, relapse rate or overall survival.

Demethylating Agents:

1. Issa JP et al. Results of Phase 2 randomized study of low dose decitabine with or without valproic acid in patients with myelodysplastic syndrome and acute myelogenous leukemia. *Cancer.* 2014; Oct 21 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/25336333>)

Decitabine as a single agent (20 mg/m²×5 d every 4–6 weeks) was tested against its combination with oral dose of valproic acid (50 mg/kg×7 d every 4–6 weeks). The rates of complete remission, overall response and overall survival were comparable between the groups. The study concluded that addition of valproic acid did not improve the outcomes of decitabine treatment.

2. Lübbert M and Kuendgen A. Combining DNA methyltransferase and histone deacetylase inhibition to treat acute myeloid leukemia/myelodysplastic syndrome: achievements and challenges. *Cancer.* 2014; Mar 24 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/25336205>)

In the light of previous data on the combination of hypomethylating agents with HDAC inhibitors, the present editorial provides potential arguments for the lack of combination benefit described in the study of Issa et al. The editorial suggests that valproic acid may not be a strong HDAC inhibitor, the intermittent schedule of valproic acid used might have led to suboptimal systemic drug exposure as compared a continuous regimen used otherwise, and importantly, the HDAC inhibition may arrest DNA synthesis and hence lowering the incorporation of decitabine and reducing the therapeutic index of the latter.

3. Duong VH et al. Lack of objective response of myelodysplastic syndromes and acute myeloid leukemia to decitabine after failure of azacitidine. *Leuk Lymphoma.* 2014; Sept 27 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25263320>)

A single center study with 25 MDS/AML/MDS-MPN patients administered decitabine subsequent to primary or secondary azacitidine failure, and yielded stable disease

in 5 patients and no complete/partial response nor hematologic improvement in any patient. Median number of decitabine cycles administered was 2 and disease progression was rapid.

4. Bejar R et al. TET2 mutations predict response to hypomethylating agents in myelodysplastic syndrome patients. *Blood.* 2014; 124(17):2705–2712 (<http://www.ncbi.nlm.nih.gov/pubmed/25224413>)

The study sequenced 40 recurrently mutated myeloid malignancy specific genes in 213 patients prior to treatment with azacitidine or decitabine. The response to treatment correlated with TET2 mutations especially in the absence of ASXL1 mutations. Furthermore, the TET2 null cells lost engraftment advantage in murine bone marrow in presence of azacitidine. The TET2 mutations may thus predict response to hypomethylating agents. Besides, mutations in TP53 and PTPN11 associated with poor survival but not with drug response.

5. Xie M, Jiang Q and Xie Y. Comparison between decitabine and azacitidine for the treatment of myelodysplastic syndrome: a meta-analysis with 1392 participants. *Clin Lymphoma Myeloma Leuk.* 2014; Jun 12 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25042977>)

The meta-analysis included a total of 1392 MDS patients (decitabine, n=768; azacitidine, n=624), from 11 clinical trials. The pooled estimates of complete response rates, PRBC transfusion rates and incidence of grade 3/4 toxicities were comparable between the two drugs. However, rates of partial response, hematologic improvement and overall response were higher with azacitidine as compared to decitabine. Azacitidine also showed superior outcome in patients with high risk features or age >75 years.

6. Müller-Thomas C. Response to azacitidine is independent of p53 expression in high-risk myelodysplastic syndromes and secondary acute myeloid leukemia. *Haematologica.* 2014;99(10):e179–181. (<http://www.ncbi.nlm.nih.gov/pubmed/24972774>)

The present retrospective study assessed p53 expression by immunohistochemistry in bone marrow biopsies of 100 MDS/secondary AML/MDS-MPN patients prior to the start of azacitidine treatment. p53-positive patients mostly belonged to the poor risk category and often had a simultaneous presence of chromosome 5 abnormalities. MDS patients with strong p53 expression showed higher response rates to azacitidine as compared to p53-negative patients (p=0.033). No such difference was noted in secondary AML cases

studied. However in MDS, the overall survival was shorter in p53 positive patients despite responding to azacitidine.

10. Grinblatt DL et al. Patients with myelodysplastic syndromes treated with azacitidine in clinical practice: the AVIDA® registry. *Leuk Lymphoma*. 2014; Aug 20 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/24956145>)

A community practice registry provides real world evidence supporting the efficacy and safety of azacitidine in 421 MDS patients with lower as well as higher risk disease.

11. Svensson T et al. A pilot phase I dose finding safety study of the thrombopoietin-receptor agonist, eltrombopag, in patients with myelodysplastic syndrome treated with azacitidine. *Eur J Haematol*. 2014;93(5):439–445 (<http://www.ncbi.nlm.nih.gov/pubmed/24853277>)

Previously untreated MDS patients (n=12) eligible for azacitidine treatment and who had <75×10⁹/L platelet count were included in this study. The severe adverse events included infections, deep vein thrombosis and transient ischemic attack. The MTD was determined at 200 mg qd. Complete remission or bone marrow remission was seen in 4/12 while platelet improvement was seen sustainably in 9/12 patients.

12. Seymour JF et al. Bone marrow hypocellularity does not affect tolerance or efficacy of azacitidine in patients with higher-risk myelodysplastic syndromes. *Br J Haematol*. 2014;165(1):49–56. (<http://www.ncbi.nlm.nih.gov/pubmed/?term=Seymour+JF+and+hypocellularity>)

The present report was a post-hoc analysis of AZA-001 (azacitidine vs. conventional care regimen) clinical trial that assessed the impact of baseline bone marrow cellularity on overall survival. Of the total 299 patients randomized, 13% (n=39) were hypocellular (<30% marrow cellularity). Azacytidine tolerability was comparable between hypocellular patients and others. At 33 months, the median overall survival was not reached in hypocellular patients while it was 21.1 mo in non-hypocellular patients treated with azacitidine with the treatment outcome being significantly superior than the conventional care group in each of the two cellularity cohorts.

IMDs:

13. Jonasova A et al. High level of full length cereblon mRNA in lower risk myelodysplastic syndrome with isolated 5q deletion is implicated in the efficacy of lenalidomide. *Eur J Haematol*. 2014; Oct 4 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25284710>)

Previously down-regulation of cereblon (CRBN) gene expression was associated with resistance to lenalidomide treatment in myeloma. The present study demonstrated that del 5q low risk MDS patients had significantly higher levels of CRBN mRNA as compared to other low risk MDS patients or healthy controls. Furthermore, the CRBN expression was especially higher in responders to lenalidomide, which dropped coincidentally with MDS progression.

PATHOBIOLOGY:

14. Woll PS et al. Myelodysplastic syndromes are propagated by rare and distinct human cancer stem cells in vivo. *Cancer Cell*. 2014;25:794–808. (<http://www.ncbi.nlm.nih.gov/pubmed/24835589>)

In this seminal study, an assessment was made of somatic mutations observed in the MDS cases studied, via sequentially back-tracing in myeloid committed progenitors, to common progenitors to early stem cells. The study underscored Lin⁻ CD34⁺CD38⁻ CD90⁺ phenotype as the earliest stem cell that could propagate MDS phenotype in vivo. The study further focused on del5q- cases and found that it could be the isolated genetic abnormality in the stem cells as well as committed progenitors particularly early in the disease. The study also alluded to additional driver mutations like TP53 gene mutations occurring in the stem cell itself and/or in downstream progenitors that may offer self-renewal ability and may coincide with the process of disease progression and leukemic transformation.

15. Chen X et al. Induction of myelodysplasia by myeloid-derived suppressor cells. *J Clin Invest*. 2013;123(11):4595–4611. (<http://www.ncbi.nlm.nih.gov/pubmed/?term=Chen+X+and+myelodysplasia>)

The study demonstrated expansion of myeloid-derived suppressor cells typically linked with immunosuppression/inflammation, that via S100A9-CD33 ligand receptor pathway engage other immature myeloid cells into secreting suppressive cytokines like IL10 and TGF β , which in turn may lead to marrow failure and multilineage cytopenia as shown by the study in a transgenic mouse model. Lastly, the study also demonstrated that disruption of CD33 signaling or all trans retinoic acid-induced maturation of these suppressor cells, could rescue the MDS phenotype in mice.

16. Scopim-Ribeiro R et al. Ten-Eleven-Translocation 2 (TET2) is downregulated in myelodysplastic syndromes. *Eur J Haematol*. 2014;Sept 8 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25200248>)

As compared to normal bone marrows (n=22), the bone marrow cells of MDS (n=64) and AML (n=53) showed significantly decreased TET2 expression. Among MDS patients, RAEB-1/RAEB-2 patients especially showed lower expression of TET2 as compared to the other WHO 2008 MDS classification categories. Also, the leukemic progression coincided with a further drop in TET2 expression and in a multivariate analysis along with the WHO 2008 classification categories and male gender, loss of TET2 expression too predicted poorer overall survival.

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.

17. Fenaux P et al. Myelodysplastic syndromes: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. *Ann Oncol*. 2014;25(suppl.3):iii57–iii69 (<http://www.ncbi.nlm.nih.gov/pubmed/25185242>)
18. Porwit A et al. Revisiting guidelines for integration of flow cytometry results in the WHO classification of myelodysplastic syndromes—proposal from the International/European LeukemiaNet Working Group for flow cytometry in MDS. *Leukemia*. 2014;28(9):1793–1798. (<http://www.ncbi.nlm.nih.gov/pubmed/24919805>)
19. Bejar R and Steensma DP. Recent developments in myelodysplastic syndromes. *Blood*. 2014; Sept 18 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25237199>)
20. Tefferi A. Primary myelofibrosis: 2014 update on diagnosis, risk-stratification, and management. *Am J Hematol*. 2014;89(9): 915–925 (<http://www.ncbi.nlm.nih.gov/pubmed/25124313>)
21. Duong VH, Komrokji RS and List AF. Update on the pharmacotherapy for myelodysplastic syndromes. *Expert Opin Pharmacother*. 2014;15(13):1811–1825 (<http://www.ncbi.nlm.nih.gov/pubmed/25080144>)
22. Gale RP, Bennett JM, and Hoffman FO. Therapy-related AML: A slip of the lip can sink a ship. *Leuk Res*. 2014;38(3):418–420. (<http://www.ncbi.nlm.nih.gov/pubmed/24439054>)

We would like to thank Suneel Mundle, a member of the MDS Foundation, and Rhea Mundle for their assistance in monitoring these important peer-review publications on MDS.

MDS AWARENESS

KAREN A. WENZEL MEMORIAL GOLF TOURNAMENT

7th Annual Karen A. Wenzel Memorial Golf Tournament – A Son's Love

This past August 16th we held our seventh annual charity golf tournament, in memory of my beloved mother Karen A. Wenzel who passed away in 2006 from MDS. My mother was diagnosed with MDS in February of 2006 and was told she needed a bone marrow transplant. Due to a donor backing out last minute and an unknown infection, she succumbed to the disease 4 short months after being diagnosed. Eight years later we are trying to do something, anything, to help find a cure for this disease. I am so thankful for the annual golf tournaments and the people who make them possible. As in years past, family and friends get together to remember my mother, enjoy a few laughs, and help raise some money for the Myelodysplastic Syndromes Foundation. To date we have raised approximately \$30,000. Looking forward to many more years ahead!

Paul Wenzel, Jr.

Weymouth, Massachusetts



We have raised approximately \$30,000!

ORGANIZE A FUNDRAISER

Like Paul, you may want to create and organize a special event that increases awareness and makes a difference. There is no right or wrong way to do it. You can design a fundraiser that fits your interests and your timeline. We are encouraging everyone to be creative and help spread MDS awareness in any way you can think of. Just get in touch with us and we can provide you with MDS materials. Help spread awareness and support MDSF programs and services! Have you told someone about the MDS Foundation lately? 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 YEAR-ROUND!
THANK YOU FOR YOUR SUPPORT!

PATIENTS & CAREGIVERS LIVING WITH MDS FORUMS

SPREADING THE NEWS WORLDWIDE



HIGHLIGHTS FROM OUR 2014 INTERNATIONAL MDS FORUMS

Jacksonville, FL ■ San Francisco, CA
Columbus, OH ■ Sao Paulo, Brazil
Chicago, IL ■ St. Louis, MO
Winston-Salem, NC ■ New York, NY
Houston, TX ■ Minneapolis, MN
Taiwan ■ Bologna, Italy ■ Pavia, Italy



Global MDS Patient Support Groups

The overwhelming success of our Patients & Caregivers LIVING with MDS Forums 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.

PLANNED FUTURE EVENTS 2015 – LOOK FOR US IN A CITY NEAR YOU!

January 31: San Diego, CA
February 28: (Rare Disease Day)
Miami, FL
March 14: Nashville, TN
April 18: Pittsburgh, PA

May 2: Washington DC
June DTBD: Vienna, Austria
June 27: Hackensack, NJ
July 18: Cleveland, OH
August DTBD: Indianapolis, IN

August DTBD: Philadelphia, PA
September DTBD: Atlanta, GA
October 24: New Haven, CT
November 7: Westwood, KS
DTBD: Armenia

*Please make sure to regularly check our website for details.
Contact Deborah Murray 1-800-637-0839 Ext. 203 dmurray@mds-foundation.org for reservations/inquiries.*

CARING AND COPING

OUR CAREGIVER STORIES

Rochelle's Journey

Rochelle Ostroff-Weinberg
Wynnewood, Pennsylvania

The diagnoses of my husband Bob Weinberg in 1998 at age 48 with MDS-RARS (refractory anemia with ringed sideroblasts) created shock waves too extreme to be able to comprehend. How does one absorb and process the prognoses stated matter-of-factly by the oncologist that your husband will die in one to ten years? My existence was suddenly totally and infinitely transformed and that existence would never return to what most people consider living a normal life.

Bob and I had always expected to retire in Paris or on the French Riviera. We had spent so much time in France since 1976, the year where he came over to Strasbourg to woo me and bring this expatriate back to the States. Hearing Bob say — almost as a mantra — “I won’t make it to retirement” was both incomprehensible and devastating. Over the years, from the point of his diagnoses to his final hospitalization to try to cure his MDS converted Leukemia I was — and I am not ashamed to admit — frantic, afraid and at wits end as to how to help. I felt so helpless and out of control, for how does one go about daily living when your mind is over consciously aware of your husband’s illness, suffering, physical and emotional metamorphoses, as well as his impending descent toward death? MDS became an additional being, like an unwelcome house guest who won’t leave, like an omnipotent intruder in my marriage.

As Bob fought to stay alive through transfusions, long distance trips to participate in medical trials, chelation treatment and involvement within the MDS Foundation, I was at his side. I watched him seek every possible approach to enable him to live a “regular” life in spite of a disease that syphoned his energy and mine, a disease more powerful than he. And I watched his heroic acts with the MDS Foundation where he put his all into



helping others struck by MDS, providing tools for them to learn where to turn for treatment and information.

In 2011, while living in Menton, France with Bob during my professional sabbatical, I had an epiphany of sorts. Bob was being transfused weekly at Princess Grace Hospital in Monaco where I would wait for him. On the wall of the waiting area was a poster whose message was addressed to the family of cancer patients; it offered a 24 hour website where family needing support handling the anxiety of living with someone struck by cancer could reach out for help. Although I never made contact with the service, it brought to my consciousness that I needed such help. Simply being aware that the service is there brought solace and degrees of relief. I still think, even now, about contacting the organization. That opened for me a window.

When Bob died on April 27, 2013, I made a pledge to create a program that would offer MDS patient spouses the supportive help that I myself needed over the 15 years of Bob’s illness. I understood that I was called to carry on Bob’s work for the MDS Foundation, as well as to provide a venue where MDS family members would feel supported as they embarked on a dark and lonely voyage, an exhaustive and draining trek. So, I created the MDS Family: Coping and Caring events, organizing the first event at the end of July 2013, three months after Bob’s death, with a three cycle structure each year.

At each of the four events that have taken place (in July 2013 and 2014, October 2013 and April 2014) the participants have expressed their appreciation of the embracing program where they can speak openly to others who share their turmoil, concerns, fears, frustrations and questions. Each event creates a bond of camaraderie, while providing a support network of spouse to spouse, patient to patient and family to family. An essential distinction that sets these events apart from the patient forums and other patient oriented programs is that The MDS Family: Coping and Caring focuses on the human level, on the fundamental questions “Where do I turn to express my concerns and distress?” And “Who is there who can understand what I am experiencing?”

Several critical elements that I have extracted from all of the events is that the members of the MDS family—be it the patient, the spouse, the adult child of the patient or the son-in-law—feel compelled to share their story, to hear about the experienced of other MDS families and to ask questions directly to others who are living on some or many levels what they are living. The homey ambiance created by sitting together in the living room or at the table over a nice meal inspires openness and connectedness. The personal side of the medical experience is brought to the fore, prompting deep listening and bonding. You can almost hear the listening. There is an intensity to listening and learning how others cope. At the same time, there is a relaxed and family aura that develops over the course of the event. The conversation and sharing flow. At the end of each, no one hurries off, rather there is a lingering that bespeaks a warm desire to stay connected to this newly formed “family”.

I often reflect on how Bob would react to this program. Bob loved life and wanted to live many more years than the MDS allowed. I believe that he would see this program as providing light to the lives of those with MDS and to their families.

OUR CAREGIVER STORIES

Since Bob loved life so much, to honor him and his memory, on the first anniversary weekend of his death, April 26 2014, I organized the third MDS Family: Coping and Caring event. I held this Anniversary Memory event at the *White Dog Café* in Philadelphia because “The White Dog” has been a favorite restaurant of ours for more than 20 years. Over that entire weekend, to further honor Bob’s memory and zest for life, I organized a set of three events, from Friday night dinner at my home to a jazz evening at Chris’s Jazz Club, capped with Sunday Brunch for Bob’s closest high school buddies, coming in from Canada, New York and South Carolina.

My journey continues with each MDS Family: Coping and Caring event as a benchmark. It is the way that I have now to reach out to Bob by touching the lives of those in the MDS Family.

I feel deeply indebted to all in the MDS Foundation with whom I collaborate and who support this venture. I feel deeply indebted to Bob for all that he taught me and others by living his life without limits. And I am so completely indebted to my wonderful daughter, Daniella, who supports me so totally and provides me with strength and great love.



Coping and Caring Luncheon, Philadelphia, PA



Coping and Caring Luncheon, Margate, NJ

HERE'S WHAT ATTENDEES ARE SAYING ABOUT THEIR COPING AND CARING LUNCHEON EXPERIENCE

“It is my honor to witness the strength, compassion, thoughtfulness and generosity of such a special group. In your presence, I experienced the deeper beauty of human resiliency.” Sudha Allitt (meditation leader)

“Thank you for bringing us together in a very supportive group, very informative and helpful.”
David Sacks (son-in-law to Lois Barnett, MDS patient)

“As always, a most informative and lovely afternoon..” Eileen Rothstein (wife of Paul Rothstein, MDS patient)

“The exchange with other MDS patients and their caregivers was very encouraging and helpful.”
George Mackey (MDS patient)

“Thank you for a beautiful session. I am grateful for this session where everyone shared their experience, knowledge, and support. I had not met other people who have MDS; so this is a big eye-opener. I learned a lot and say THANK YOU/Merci Beaucoup!” Julie Abrams (daughter of Lois Barnett, MDS patient)

“This was terrific... a great opportunity for me. I liked hearing from other patients and caregivers about their experiences. Very much appreciated.” Anonymous

“We appreciated that we can talk — like family — around the living room...” Anonymous

OUR CAREGIVER STORIES

I am a Caregiver...

**Patrice King Brown
Laguna Niguel, CA**

I never heard of MDS until I fell in love.

For more than twenty-four years, at that time, I had been a successful Talk show host, a health reporter and a news anchor for the CBS affiliate, KDKA-TV, in Pittsburgh. It was my job to know things — to be aware of what was going on in the world and to share that information in the clearest, kindest, most accurate way that I could. And yet, I had never heard of MDS. I knew nothing of it until Dr. Paul Nemiroff came into our newsroom — and my life.

It wasn't the first thing that I learned about him. In fact, if we hadn't fallen in love I might never have known it.

Dr. Paul, as we called him, had moved from Los Angeles, where he had been the Chief Medical Correspondent for the CBS affiliate there. This was after a stellar career as a nationally recognized Head and Neck Cancer Surgeon. He is also a PhD in Behavioral Sciences. Clearly, a brilliant man. People wondered why he was no longer practicing medicine. We were told that he had moved to Pittsburgh to be closer to his daughters who lived there. Pittsburgh was not where he wanted to be but his girls were there so he made the sacrifice. He gave up his life to be near them. I remember thinking, "What a great Dad". Few others would ever do that.

None of us knew that practicing his very profession could cost him his life because of exposure to the very sick people he was trained to treat. His immune system was compromised.

He fit nicely into our newsroom. Everyone liked him. And he was a terrific communicator. He easily broke down "doctor speak" so that our audience could understand the sometimes complicated medical stories. And as a surgeon we knew what he reported was accurate. He questioned every source—even the Associated Press to make sure things were right and clear. We became friends. Truly,



just friends. But over the next year or so, over coffee and sometimes between newscast dinners we became more.

One night, between newscasts he shared his story of MDS with me. That is the first time I heard the words Myelodysplastic Syndromes. He told me he had come to be with his girls because he didn't know how long he had. He had been told he had a short 18 months to 2 years and to get his affairs in order. I knew there had been days that he didn't feel well. Days of tremendous fatigue, but I never imagined something that would take my new love away from me. He wanted me to know he didn't know how long he would be around.

My perspective on life may be considered simplistic by some, but I have always believed that people come into our lives for a reason, a season, or a lifetime. I told Paul that I didn't know how long I had either. None of us knows. So the goal is to enjoy whatever time we have, accomplish what we can and have some fun along the way, if you can.

A little more than five years later we got married.

Paul had already beaten the odds. He had been told by some of the best and brightest that his time was short. He approached this news as he approaches everything — remember, he's a scientist first. He researched and interviewed and studied and tried to find a way to save his life. (His story is available in a book he has written called *NINE LIVES: A Story of Survival and Hope: Overcoming*

Obstacles, Labels and Beating the Odds (Drpaulspeaks.com on Amazon.com) He is accepting no profits from his book. The publisher has agreed to donate some of the proceeds to the MDS Foundation.

But my life has changed tremendously. I am now, also a caregiver!

Over the next several years after our marriage I became more knowledgeable about MDS. I carefully watch him daily for signs. Is this a good day? MDS has created new normals for me as his caregiver.

I wasn't sure what to expect from life with MDS. What I constantly do is try to remember to be grateful for the good life we have. There are challenging days but for the most part Paul is doing well. And for that I am truly grateful.

There is an underlying anxiety that any day can bring on the onset of a "bad stretch" but I choose not to live in fear. We try to make each day together count. My husband is still my partner and he is a great one. You have to make sure you don't lose your relationship. That is the most important thing — keeping your love alive. We do as much as we can as often as we can. I would recommend that for you as well. Try not to let the illness rob you of good times with the person you love.

Little things can become bigger problems. Often he has hot flashes. But where my midlife hot flashes may last a few moments, his can go on for hours. Between us we keep the house cool. My brother, Dave, once joked, "Hey you guys, you could hang meat in here!" We make jokes and I bring him cool cloths. Night sweats and mouth ulcers, which I found are common with MDS patients, can be an issue so we don't eat much spicy food. We adjust. We don't focus on the illness.

I do whatever I can to help keep him comfortable. Some days he has tremendous fatigue. He beats himself up about those days, saying he isn't accomplishing anything. I reassure him that it's okay. Nobody dies if he doesn't get something done. And that may be a day we read together or watch a movie. Or I experiment

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in the kitchen and we try to enjoy each other's company. And we do. He gives so much to me, too, he's a true partner in every sense of the word. Even when he didn't feel particularly well, he accompanied me to receive my EMMY for Lifetime Achievement in Broadcasting, but we didn't go to the "after-parties." It didn't matter, I was so glad he was with me.

We go to doctors more than most people and as his advocate, his caregiver, it is important that I go with him and take notes. You will find most patients don't really hear all that a doctor is telling them. It's important that I do. I am often frustrated by the medical system, even though my husband knows how to navigate it. We met one young doctor who came in with his ipad and immediately began asking questions and typing, never once looking at my husband. I know they are pushed for time. I know they are stressed. So I very calmly, but firmly, asked him if he was ever going to actually look at my husband — his patient. He did. I will always fight for my husband because sometimes he is just too tired.

Sharing this with you is a bit challenging for me. Even though I was in the homes of millions of people over the years through television, I remain a very private person. MDS has changed some of that, too. I share our story in hopes that it will encourage someone who is also living with MDS, or has a loved one who is. I remind you, as the airlines say, to "take your oxygen first" then take care of your spouse. By that I mean, enjoy life when you can. Talk to friends, read a good book, enjoy the sunshine — simple things that can help you to be strong. Find ways to keep yourself feeling good and alive. As the caregiver, you have to recharge. Be honest with your spouse or loved one about that. Small breaks can truly make a difference in both of your lives.

One of my mottos is "We must have something to do, something to look forward to and someone to love." These days I have them all. None of us knows when life will change. It can change with every breath we take. I know my life

**One of my mottos is
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with every breath we take.**

changed dramatically the day Dr. Paul Nemiroff walked into our newsroom. He brought me joy and challenges and love. I am so glad that he did.

My Role as Aldeane's Caregiver...

**Peet Sööt
Lake Oswego, Michigan**

Being a chemical engineer has its advantages and disadvantages. Being an engineer who never leaves his analytical thinking behind has hopefully helped my wife in her struggle with MDS and its subsequent side effects. Being an engineer who does not turn off his brain during difficult times can wear one down.

I am not sure if it was to occupy my mind or I actually thought that I was going to be of some help, but I started tracking my wife's medical data from the early days of the transplant. I have now accumulated nearly twelve years of data and graphs, tracking everything from simple blood counts to liver enzyme levels, the latter to make sure that some medications are not adversely affecting her internal organs.

I remember visiting a caregiver support group after the transplant. I did not last more than a meeting. I could not relate to caregivers who only knew that their wife

had to take a white pill every so often. Was there truly nothing more they could do for their loved one? How can one sit by so passively when the patient is undergoing such a trauma? Much of the tracking is not engineering. It is simply an interest to be involved.

Maybe my approach was too intense, but it was also fulfilling. That was especially the case when my graphs of data would show trends and I could actually anticipate some outcomes. Unfortunately, that sometimes led to arguments with the medical service providers. Even during the transplant hospitalization, there were running dialogues about the lack of efficacy of the anti-nausea medications. I had gotten totally frustrated with their shotgun approach and finally got a doctor to listen to my more methodical review of the correlation between bouts of nausea and which medication had been administered.

Other times, I have forecast the need for some intervention, only to be rebuffed by medical staff since the medical data had not yet crossed the line to an unacceptable level. I did not expect to be right all the time, but was simply asking the service providers to consider the possibility that an event would happen. There was even once that a laboratory test was incorrect. It had falsely shown my data trend to have been stopped. It was not a pleasant experience to subsequently find out that my trend was right, Aldeane should have had a certain injection on a Friday—as I had forecast. Only on Monday did we find out that the previous laboratory result was improperly analyzed and she was called to the hospital immediately to give her the injection. Of course, she survived but, the upset was a bit hard to handle at the time. And, our frustration with this incident was offensive to the doctor, as he told us in no uncertain terms. Rather than acknowledge that a mistake had been made on the service side, we were berated for not being quiet sheep.

Don't get me wrong, most of the doctors and nurses have been fantastic and it has

OUR CAREGIVER STORIES

been a wonderful journey of mutual respect and cooperation. It has been an absolute pleasure to work with the doctors who accept, and even encourage, patient and caregiver involvement. But, it is still frustrating when one has to deal with some personalities, or attitudes, which are not compatible with your own approach.

The journey has had lots of peaks and valleys. The wonderful thing is that there have always been peaks after the valleys. After the transplant, the MDS had been cured. The struggles changed to the battles with GVHD and other ancillary illnesses. In the last five years, the most frequent problems have been with pneumonia. Aldeane has written in her letter to the Foundation about how there were numerous cases of pneumonia in 2009/2010, seven to eight years after the transplant. Her immune system has never recovered to its original levels.

We thought we had the pneumonias solved, after she underwent two sinus surgeries. That was to allow the sinuses to drain and not provide pools where infections could get started. She was pneumonia-free all of 2011 and 2012. Unfortunately, I had let my guard down. It was a rude awakening when she started spiking a fever in May, 2013. The same old issues arose quickly. As she lay on her bed with the temperature rising, when would it be time to go to the hospital? We waited too long. By the time we decided to head for the hospital—she could no longer get out of bed on her own. There was no way I could get her to the hospital. It was time for a 911 call. Six days later, most of it in the ICU, she got to come home again and we were once again on a peak—or at least a plateau.

It is interesting what unexpected perspectives you get in a hospital. Aldeane's motorized bed in the ICU broke down at one point. Lo and behold, there was a crane mounted on the ceiling. That was used to lift her up by a sling which was underneath the bedsheets. The new bed was rolled under her as the broken one was taken away—all while she was nestled in the sling half way to the ceiling. It was

sobering to hear that this is often used to simply move patients who are so obese that the nurses are unable to move them, even from side to side. Amazing what the hospitals have to, and do, accommodate in our modern society.

So the 2013 pneumonia was a wakeup call. I could no longer drift away from my caregiver role. I will have to remain alert. I had to reestablish my data tracking mode and make sure that I am not caught off guard again.

One of the most difficult things for a caregiver, at least this one, is the psychological battles the patient goes through. Unlike the medical issues, there is not

much I can do to help with the psychological matter, other than try to stay positive. It is difficult when things are going well, or at least not badly, and yet the patient struggles with the mental battles. That can be an issue between the patient and caregiver: the different perspectives. Remain patient with the patient.

Sorry for the negative tone of most of this letter. Life is good! Given the positive outcome, the journey has been fulfilling, a chance to help somebody, a chance to make a difference. Thank you God for the peaks—and even for the valleys. Without the one there is less by which to judge the other.

SHARING IS CARING...



Look at those wonderful stem cells, 4.5 million! Now we wait and pray. My husband Steve was the donor for his brother, Richard. Priceless photos. The night the transplant began, we played the song *Happy*, very touching for us all!

Alison Kahn, Lighthouse Point, Florida



ClinSum		Date Range: 10/07/2014
Molecular Pathology		22:38
Donor ID 1	[Multiple]	
CD3 Diagnosis	MDS	
CD33 Diagnosis	MDS	
CD3 Donor 1 Result	100.00 %	
CD33 Donor 1 Result	100.00 %	
CD3 Interpretation	CD3 Interpretation	
CD33 Interpretation	CD33 Interpretation	

LATEST UPDATE:
SO FAR...
SO GOOD!

PATIENT STORIES

OUR PATIENT STORIES

An Update from Aldeane

Aldean Sööt
Lake Oswego, Michigan

I had heard I had MDS after a routine medical checkup. This was in late August of 2002. I took no time deciding a stem cell transplant was my only chance of survival. I had been given 18 months to live. I chose to go to Fred Hutchison Cancer Research Center in Seattle for my transplant, 170 miles from home. I had my transplant on November 27, 2002 a mere 3 months after diagnosis.

I wrote my first article for *The MDS News* back in 2005 when I was three years out. At that time I had just finished my last cyclosporine and felt my MDS was in check and gone. Nine years later I now know for sure that I was correct in my assumption that my MDS was gone. Unfortunately, I had some further battles to fight with my Graft vs Host Disease (GVHD).

I got GVHD manifesting as scleroderma. My extremities were becoming stiff. I could no longer bend over to pick something up and my breathing was becoming labored. I chose to take Rituxan to fight the GVHD and tried deep muscle massage to try and break down the scleroderma. Unfortunately, the massage did not help. After further consultation with doctors, I went to a physical therapist. She tried some techniques and finally moved to Asian cupping, a therapy she had never done before. It was a very painful option, but it was the only one that worked. My therapist would suction the cup to my skin and then slide the cup along my skin to break the grip the scleroderma had on the underlying tissue. It took at least 7 months for me to become free of the scleroderma bands that were keeping me stiff. I subsequently was able to completely recover normal body movement.

I also had problems with infections in my nose causing me to get pneumonia. The infections in my sinuses would drain down



my throat and some of the fluids would get into my lungs, causing the pneumonias. In 2009 and 2010 I had pneumonia 5 times. During that period I was continually consulting with doctors to find a way of avoiding the pneumonias. Finally, my Ear, Nose and Throat (ENT) Specialist recommended sinus surgery. I had two nasal surgeries to open up my sinuses so they would drain more easily and not provide the stagnant pools where infections would begin. That effectively solved the problem. After the surgeries, I still had to rinse my sinuses twice a day to wash out any starts of infections. As tedious as that was, I was willing to do it to avoid the pneumonias.

Also, in 2009 I had my gallbladder removed and I had a hysterectomy. What a year.

**Although it seems I have
had a lot to deal with I am
happy no one is saying
“you have 18 months to
live” as they did when I
heard I had MDS... Nothing
comes easy in this world;
you have to work for your
own well-being.**

Unfortunately, I dropped my guard and in May 2013, after having merely overlooked a couple of days of sinus rinses, I was in the ICU with a very serious bout of pneumonia. I had not been keeping good enough track of my temperatures and tiredness and it got away from me. Six days in ICU was enough to remind me never to skip the sinus rinses ever again and to stay ever alert to what my body was telling me.

I have learned over time to listen to my body. When I feel something unusual, I pay attention! Fortunately, my infectious disease doctor started giving me a prescription for antibiotics so I would have immediate medicine when I felt the onset of a fever. If anything felt unusual, I would take my temperature every day. This has worked very well for me. There is no one better than me to know what my body is doing. If I get a fever above 101°F, I immediately take my antibiotic.

I have mostly kept on top of things in the last year. It is now 2014 and I am doing very well although my immune system has still never totally recovered. I have undergone testing of the immune system and am currently undergoing a six month treatment with IVIg to bolster my immune system. This is likely also helping with the lack of pneumonias since last May. And, I am now continually taking a moderate dose of antibiotics. If I ever have an elevated temperature I immediately switch to a higher dose of antibiotic and it has kept me from getting pneumonia again.

I feel great and do most of what I want to do. I try to stay away from large crowds of people I don't know, since I am still dealing with a not so perfect immune system. Although it seems I have had a lot to deal with, I am happy no one is saying “you have 18 months to live” as they did when I heard I had MDS. I am completely pleased I chose to get my transplant as soon as possible when I was diagnosed. Nothing comes easy in this world; you have to work for your own well-being.

A Different Perspective...

Paul Nemiroff, PhD, MD, FACS

Laguna Niguel, California

www.drpaulspeaks.com

As a Head and Neck Cancer surgeon, I was usually on the other end of the “sharp” objects, and the one who was usually “in charge.” But I certainly could not have imagined in a million years that, in one instant, my life was about to change and the doctor was to become the patient. Today, after 15 years with MDS, and after being told initially that I would probably only survive for 2 years, I thought it was time to share my story with others who are battling this disease.

I think I can give you a better idea of where I was in my life, what I was feeling, and what went through my mind the day I got “The Phone Call”...*[Excerpt from Dr. Nemiroff’s book: Nine Lives: A Story of Survival, and Hope: Overcoming Obstacles, Labels and Beating the Odds. Available from amazon.com]*

I’d just finished giving a lecture to a group of middle school kids about the “evils” of cigarette smoking and was feeling pretty good about myself—a head and neck cancer surgeon doing his best to convince a bunch of wonderful 8th graders that lung, throat, and oral cancer were killers you could avoid, just by making smart decisions. It was the Great American Smoke-Out Day around the country, devoted to educating young people about the perils of tobacco.

I had just turned 50 and was reeling and in shock from a recent divorce, which resulted in my children being pulled away to another state—however I was flying to see them every other weekend, much to my physical and emotional exhaustion. I had a booming medical practice and was thinking about running another marathon. But I had to admit I wasn’t feeling 100% lately—if it wasn’t night sweats or fevers, it was some upper respiratory nonsense.



Patrice and I in Palm Springs, CA

Recently I had been hospitalized with something called “pneumococcal pneumonia,” a nasty number that could very well have killed me. I chalked it up to age and overwork. I thought, “You get over it and move on. It happens to everyone.”

As I was turning my car into the Edgewater Complex, with thoughts of an early evening run, my car phone rang. The voice on the other end was Dr. Richard Gualtieri—friend, physician, and all around good human being. It was 3:31 p.m. on November 18th, 1999, and the way I looked at the world and my life was about to change forever.

“Hey Rich, what’s up?” Rich wasn’t in the mood for small talk, and his tone was grave. “Where are you?” he asked. “I’m in the car, heading home.”

“Pull over for a second, Paul. We need to talk,” Gualtieri said.

There are moments in our lives that forever change us—and this was one of them.

There are moments in our lives that forever change us—and this was one of them. I pulled over next to the parkway and turned off the music. As Rich began to speak, my mind went numb.

A couple of weeks earlier, on November 5, I’d had a bone marrow biopsy based on the fact that I was having numerous infections, and a relatively low white blood cell count. I hadn’t thought too much about it—however, for perhaps a year or so, I had been getting a lot of infections—and had quietly been getting my blood cell counts measured.

I noted that my white counts, the ones that fight infection, were relatively low. Previous insurance physicals usually had mine around 8500, now they were frequently down to 3000–3500. It seemed to occur about every 4–6 weeks—and I figured it must be something called “cyclic neutropenia,” which refers to a benign condition where your white cell numbers can cycle up and down. Somewhat naively, I had told my oncologist friend Rich, why not just give me a shot of Neupogen®—a drug they give people undergoing chemotherapy to boost their white blood cell production. I was just tired of being sick. Rich, appropriately, was reluctant to do that, being the good doc that he is, and insisted on doing a bone marrow biopsy to make a proper diagnosis.

“It’s probably nothing,” he said, “but let’s just do a routine bone marrow biopsy.”

“Those are no fun,” I said. “I’ve done them on patients myself.” He reassured me, “Don’t worry about it.” On November 5th, they booked me for the procedure under a “phony name,” since I didn’t want anybody thinking I was sick or anything. Besides, it was just a “routine bone marrow.” I didn’t think that much of it. I remember laughing as I was being wheeled into the procedure room for the test, because I wasn’t the one “scrubbed,” and was in one of those patient gowns—with the back open—causing one to feel and look “very exposed.”

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The procedure went well—no problems—and that was about it. They said they would call me with the results. I didn't think about it much until that fateful phone call on November 18th. When the phone rings and you hear a solemn, foreboding tone of your personal physician saying, "We need to talk"—it stops you in your tracks.

Rich suspected I had a malignant blood disorder called Myelodysplastic Syndrome, or "MDS." MDS consists of many different types and forms—and all can be deadly. At one time, they were called "smoldering leukemia" or "pre-leukemia," but today it is considered as a form of blood cancer, with no real cure, except the possibility of a bone marrow transplant in some very limited cases.

MDS has many symptoms and signs, one of which is not being able to properly fight infections. Thus, being exposed to people with wound infections or respiratory infections, or for that matter any kind of infection, would put my life in peril. At that moment, I began to realize that not only did I have a life-threatening illness, but also that I would be putting myself in harm's way by practicing my very profession. I was going to potentially lose my life—and in the process also lose my identity as a surgeon.

I asked Rich to repeat the diagnosis several times. My knowledge of MDS, at that time, was very limited, so when I asked him how serious it was, he said, "I've never really told anybody the details over the phone—I'll tell you tomorrow." I responded, "You just told me how serious it is. How long?" He was quiet for a second then said, "Let's talk tomorrow."

Standing on the deck of my home that evening after that dire phone call of November 18th, 1999, I remember looking at the gorgeous sunset. My first thought was that I wouldn't see my two little daughters grow up. As I spiraled into this thought pattern, I began to think about



13 days before my diagnosis — Nov. 5, 1999 [getting ready for a bone marrow biopsy]

other things I might miss, like a first date for my daughters, or their graduating from high school, or simply not being able to spend time with them. It hit me that I'd better start to wake up and learn to "smell the coffee."

In my decades of practice, I had never cancelled a clinic full of patients. However, that night I called my wonderful business manager Brenda and asked her to reschedule all my appointments with other doctors in my practice. I felt incredibly selfish for doing this, but I knew the next morning I would be immersed in discussions with my oncologist friend about next steps. The doctor had become the patient.

I faced many obstacles before and after that fateful phone call but, without a doubt, that PARTICULAR DAY CHANGED EVERYTHING IN MY LIFE!

After my initial diagnosis of MDS, I began getting second and even third opinions. The MDS Foundation was helpful in providing me with information about Centers of Excellence and just providing me sources to increase my knowledge of the disease. At the time, MDS was still considered by many docs to be a bone marrow disorder but not really cancer. "Great I thought".... here comes another "label" [similar to when I was

labeled "slow" as a child]... but this label can be lethal...even though.... it's not cancer per se, but it can still kill you! Today, of course, MDS IS considered a blood cancer.

Without going through all the medical visits, the countless questions, and the fear of the unknown that I felt, I was finally diagnosed by one of the world's best on MDS, Dr. John Bennett. Dr. Bennett categorized my disease as MDS RAEB [refractory anemia with excess blasts]. I also had a number of malignant clones...of Trisomy 8 on cytogenetic testing [meaning that there were abnormalities now showing up in my bone marrow]. Also of real import is that while I had an abnormally low white count, it wasn't horrible by some standards—about 3000 [but down from the usual 8000] I'd had previously on insurance physicals over the years. I continued to get serious infections.

I was hospitalized with this for a week... and felt like 100 years old at the time. Later I discovered that my white cell count was low [I was leukopenic], but even more importantly perhaps, was that my white blood cells ability to kill invaders was markedly compromised. As most with MDS learn, a low white cell count can be a problem, but even a relatively low normal wbc count can still cause a patient

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problems if the cells themselves are not working properly.

I guess one of the ‘perks’ of being a physician and surgeon was that I was able to get in to see a number of hematologists/oncologists—one at Vanderbilt and another at City of Hope in California. The Vanderbilt visit was an especially tough one, since I had been a clinical professor of surgery there before, and the hematology/oncology department was right next door to where I used to teach residents. It was a painful/emotional time. The hematologist, a wonderful doctor there, Dr. John Greer, discussed a bone marrow transplant with me as the only possible cure. When my only sibling, my brother, was not a match, he suggested a MUD search [matched unrelated donor]. Based on the path report and my significant infections, as well as Trisomy 8 and other factors, that first it would be best to leave the practice of medicine for risk of infections. Practicing the specialty I had loved for so many years was simply a hazard to my health. Secondly, without a bone marrow transplant, if they could even find a match, my life expectancy was limited to about two years!!! That was a lonely day, driving home from the hospital. I was devastated.

The shock of being told you have a “terminal illness” can shake you and your family to the core. Questions arise — when do you tell your kids, family members, spouse, etc.? Do you share it with everybody? Clearly there is no right answer. Everyone is different. In my case, my kids were young, so I chose not to share it with them immediately.

In my case, not only was I losing part of my identity as a surgeon, but in the process would lose my life. I also felt like in some ways, I was leading a “double life,” because I didn’t want to share my illness with others. It can affect how people view you, can potentially cost you your job or position, and unfortunately, there’s still a

“stigma” some people attach to someone with any illness. Couple that with the name MDS—many people had no idea what it was. In fact, some doctors at the time hadn’t a clue.

There were days when the night sweats, fatigue, and “new normals” in my life seemed overwhelming. In time, I also became thrombocytopenic [low number of platelets]. This became a new concern along with my leukopenia [low white cell count]. I had many “new normals” in my life. I went from running marathons [26.2 miles] to not being able to run even one mile. I was that tired.

I sought out other opinions and one included the City of Hope in Duarte, CA, where they also recommended a bone marrow transplant. Given my age and other factors, the chance of survival through this ordeal was not very good. Estimated by some, that I would have an 18% chance of living a year.

I thought there must be another way. I’ve been trained very traditionally in medicine, at UCLA, Cedars-Sinai Medical Center, University of Florida, and a PhD from Purdue University, and published many research articles. However, I’ve tried to keep an open mind to new ways to treat and beat diseases. Sometimes you learn things simply by observing, but of course the gold standard must be double blind, randomized, placebo controlled studies. So I went on a quest to learn all I could about MDS and check out some ways of helping myself. It’s amazing to what lengths one will go when fighting for one’s life.

ABOUT THE BOOK

I wrote a book about my life that includes my struggles not only with MDS, but other obstacles that I’ve had to overcome in my life. It’s called *NINE LIVES: A Story of Survival and Hope: Overcoming Obstacles, Labels and Beating the Odds*. [Available on amazon.com or drpaulspeaks.com]

I wrote this book for those who have experienced paralyzing fear when their doctor said, “We need to talk.” It is for all the families to whom, as a surgeon, I’ve had to give the worst possible news. It is for those who want to join my quest to explore new ways to treat and beat cancer. I hope this book provides some solace and hope.

My main goals in sharing my book and story with you include:

1. To share some of my own struggles, challenges and victories in beating the odds not only with respect to MDS but for one’s life.
2. To raise awareness about MDS — which I believe has an “Identity Crisis”.
3. To raise funds for the MDS Foundation to continue research efforts. I should mention that I will not be receiving any profits from the book and, at my request, the publisher has agreed to donate a portion of the profits to the MDS Foundation, Inc.



Second to the last of 13 marathons I had run.
1998

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Some final thoughts...

- Get second opinions. Realize that medicine is NOT AN EXACT SCIENCE. Reportedly at the end of the 19th century in 1898, Bayer discovered a cure for morphine addiction....drum roll...it was heroin!!! GET SECOND OPINIONS!
- Have a patient advocate. Always try to have someone go with you to appointments, etc. It's hard to absorb all that is said when you may be scared to death. Fortunately my wife Patrice has been there for me.
- Seriously consider going to Centers of Excellence on MDS.
- As the patient, educate yourself. A great place to start is with the MDS Foundation.
- As a scientist, I realize that controlled studies need to be performed. I hope my book is a catalyst to encourage pilot studies on new treatments for MDS and other cancers in the quest for a cure.

As I begin my 65th orbit around the sun, now at 15 years since my original MDS diagnosis, I've asked myself: "What's next?" Who knows what's next. Learning not to just be alive, but to live. Stay tuned...still a work in progress.

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HEALTHY BODY HEALTHY MIND

NEW WAYS TO MANAGE MDS

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.*

ABOUT THE FOUNDATION

HELP US SPREAD THE WORD

Follow us on Twitter and "Like" us on Facebook.



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800-MDS(637)-0839 (within the US)
609-298-1035 (outside the US)

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 health care professionals, patients, and their families.

GET INVOLVED

Become a member, attend a forum, or join our online Patient Forum.

STAY IN TOUCH

Sign up to receive our informative eblsts and newsletters.

MAKE A DONATION

Consider making a donation to support the MDS Foundation and all we do.

VISIT US AT

www.mds-foundation.org

OUR PATIENT STORIES

Tara's Journey

**Tara Notrica
Merrick, New York**

There have been so many experiences over time, some filled with gladness and hope, others filled with grief and sorrow. Once again, I thought way back in time. There was the diagnosis of childhood asthma after an extremely severe attack at my cousin's non-air-conditioned house in the height of the summer back in the 1970's that landed me in the ER. Those were the days of the reliance on ceiling fans, because air conditioners were reserved for those who could truly afford it, and the doctors thought the heat may have contributed to the severity of the attack. Then, there was the incident of a full-blown allergic response after horseback riding during my camp visiting day. Next came the diagnosis of environmental allergies, but there was never any connection between then and now. Things quieted down during my late teen years and early twenties. The next full-blown anaphylactic episode happened during my twenties in an indoor arena at a horse event. Once again, I was treated episodically and sent on my way. I began seeing some allergists, but nothing out of the ordinary surfaced. In my mid-twenties it happened again. It came on fast and furious, the hives on my chest and back, the vomiting, the diarrhea, the facial swelling, the constriction of airways and the feeling of being scared to death. The EMT's carefully monitored me on my way to the ER, with an oxygen mask covering my face. There was the administration of IV Benadryl and a medication for my shortness of breath and this time, education about an EpiPen. My reactions were extremely severe, and it was time to be prescribed an EpiPen. Along with the prescription, once again came the referral to an allergist. My husband, who was my boyfriend at the time, and I sought out some of the best in the field of allergy and immunology. Nothing really was discovered.

Anaphylactic episodes waxed and waned over the years. I was treated with Benadryl and Albuterol and oxygen on the occasions I was taken to the hospital. Reactions came, reactions went. My husband and I got married in 1997. I got pregnant at about 2 years into our marriage and sadly miscarried. I went for a procedure after I miscarried. I came home from the day-op procedure and became violently ill that evening, once again having a full-blown attack. I was taken to the ER for symptomatic treatment. This time, it was Benadryl, albuterol and prednisone. Once again, nothing extraordinary was discovered.

In 2000, I delivered my first child, Jared. Again, reactions came and reactions went. By this point, I was treating myself with Benadryl and an inhaler when the attacks would strike, as none of the doctors who I consulted with diagnosed me with anything different. After having Jared, my husband and I tried to have another baby. For a second time, I sadly miscarried. I then had to undergo the same procedure once more, and once more, I had a full-blown episode that required an ER visit. By this point, the anaphylactic episodes became increased in severity and frequency. In 2004, I delivered my second child, Samantha. After having Samantha, the anaphylactic episodes became more and more frequent and more and more intense. Something horrific was happening, but nobody could tell me what.

On March 31, 2006, I awoke to an extreme transformation. Within days, all of my scalp hair shed, and within a few months all of my body hair had fallen out. Every muscle in my body hurt, and I became severely weakened as the days went on. More and more symptoms appeared, and by this time, I knew I was in trouble. I was affected systemically. I was displaying hypotension, autonomic dysfunction, hypoglycemia and extreme weight loss. I was becoming more and more ill. I just did not know where to turn. The endless doctor visits and countless



number of specialist consultations had begun. There were visits to my General Practitioner, Allergists/Immunologists, Dermatologists, Rheumatologists, Gastroenterologists, Cardiologists, Endocrinologists, Pulmonologists, Hematologists, Oncologists, Neurologists, Infectious Disease Specialists, Clinical Nutritionists, to name a few. We would move up the ranks until I was able to be seen by Chief of Staff Doctors, Department Heads or Directors. There were endless and invasive tests and procedures including extensive blood work, CT scans, MRI's, x-rays, PET/CT scans, painful biopsies, bone marrow biopsies, urine collections and other funky tests, depending upon the facility I was at. I visited the Mayo Clinic, Johns Hopkins, NIH, NYU, Cornell Weill, Columbia Presbyterian, Sloan Kettering, Yale, Boston Medical Center and whatever specialist or facility we thought might be able to help unravel this mystery. There were all kinds of diagnoses including Lupus, Mixed Connective Tissue Disease, Lyme Disease, Anorexia, Celiac Disease, Anaphylaxis of Undetermined Origin, Undifferentiated Autoimmune Disease, Alopecia Universalis, Good's Syndrome, Chronic B-cell Lymphoma, and even Severe Clinical Depression and Chronic Fatigue Syndrome. There were immunomodulation drugs, immunosuppressive drugs, chemotherapy drugs, long-term antibiotics, IVIG, monoclonal

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antibodies and even a radical thymectomy. Of course, the possible diagnosis of Severe Clinical Depression and Chronic Fatigue Syndrome angered me most. I certainly wasn't depressed nor was I tired. I was just very, very, very sick. As a matter of a fact, I was gravely ill at certain points and almost to the point of no return. There were times I knew I flirted with death, but somehow found the strength, courage and determination to carry on.

Throughout all of the test procedures and massive amounts of blood tests, there were only a few things that were abnormal. Blood histamine levels were at times very elevated, and my IgE levels were through the roof. Of course, the anaphylactic episodes still continued, and I was becoming more and more malnourished with each passing day. My husband and I spent each free passing moment researching to find some kind of connection. I still continued to consult with doctors, and when I became just too sick to go personally, my extensive medical file went instead, sometimes on a global track. The only thing we knew was that there was a connection with my IgE levels and this grueling multi-systemic illness.

In March 2011, after countless hours of diligent research, especially on behalf of my husband, we found a doctor who was a Mast Cell Disease expert. We had read and reread the possible symptoms and knew the glove fit. As a result of being diagnosed sometimes with the most unfitting diagnoses, we began taking pictures of some of my reactions. So, my bulging medical file, along with my photos, was sent off to one of the few Mast Cell Disease Specialists in the United States of America and even in the world. I was very quickly scheduled for a consultation appointment within days at Brigham and Women's Hospital at what is now known as The Center of Excellence for Mastocytosis and Mast Cell Activation Disorders. It took years of tears, sorrow, pain, worry, anger, doubt, fear, fright and countless other emotions to within hours finally be diagnosed with a fitting and proper

diagnosis. On April 1, 2011, I was diagnosed with Mast Cell Disease. As the tears streamed down my face, I knew in my heart of hearts this was it, but I still asked, "This is not an April Fool's joke, is it?" It was not. This was the real deal.

Immediately after being diagnosed, I began an intensive mast cell disease treatment. The treatment plan was methodically prepared, and each new drug was introduced very slowly so as not to reject the treatment that was designed to help turn my life around. There were mast cell stabilizers, H1 blockers, H2 blockers, leukotriene blockers, additional prescriptions, nutritional supplements, and lastly, an anti-IgE treatment. I could not have been more excited with the addition of each new component of the treatment plan. I hoped and prayed this would be the magic bullet.

My current treatment plan was effective at minimizing the severe anaphylactic episodes and the constant ER visits. Although this was the case, it was not enough for me. Bizarre and often dangerous symptoms still continued, and although we were treating symptoms, I just knew my body never felt right. So, my quest for a bone marrow transplant would continue. Not only was I monitored by Allergists/Immunologists but also Hematologists/Oncologists. I promised I would give my current treatment plan a really fair shake, as the doctors thought this was the best way to proceed. One year quickly passed and turned into two years. Two years turned into three years. Three years turned into possibly 5 years. At what point would we say enough was enough? Three and one-half years into the treatment, I seriously revisited the possibility of having a bone marrow transplant. Some of my Allergist/Immunologists agreed, as my quality of life was severely impacted by my disease. Some of my Hematologists/Oncologists agreed as well. One of my doctors was even successful in getting my insurance company to approve the transplant. However, before proceeding, it was

necessary to complete a bone marrow biopsy. I anxiously awaited the pathology report. According to the report, there was "a deletion of the 20q12 region of chromosome 20 in 3% of the nuclei." Furthermore, the report indicated that "this patient presented with the signs /symptoms of myelodysplastic syndrome (MDS)." I felt this new information only further validated the need for a bone marrow transplant. Just when I thought it would finally happen, I hit a huge stumbling block. The doctor that had been following me for several years was part of a facility that did not accept my insurance and would be considered out of network. So, I went to what is considered a Center of Excellence and a facility that would accept my insurance payment as payment in full. Much to my dismay, one doctor said yes, but another doctor said to watch and wait. There was also discussion of the consideration of Ibrutinib or Ruxolitinib for my case. However, this did not deter me.

I was accustomed to doing research and found the MDS Foundation online. I contacted the foundation and spoke with Audrey Hassan. She took all of my contact information and sent me a packet with tons of information. I knew my journey had not ended. Through the reading of literature, I had learned about two MDS experts in



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New York City. After speaking with Audrey and learning a little bit about both of the doctors, I knew I had to schedule consultations with them. I was quickly given an appointment with Dr. Lewis Silverman at Mount Sinai Medical Center. My husband, my cousin, who is a Hospital Administrator, and I attended the appointment. We unanimously agreed that Dr. Silverman was like a breath of fresh air. He was soft-spoken and at ease, yet we knew brilliant as well. He promised to give my case the utmost attention. To date, Dr. Silverman continues to delve into my case with his team.

Audrey also informed me about the MDS Forum that was held at MSKCC on September 20, 2014, where Dr. Virginia Klimek was the Keynote Speaker. I knew I had to consult with her as well, as I thought that maybe a female physician would view my case with a different perspective. I had already consulted with two doctors at MSKCC and now needed permission from the doctors and facility to let me make an appointment with Dr. Klimek. I was a little disappointed to be told that all three doctors had spoken about my case. I wanted this consultation to be completely unbiased. However, thankfully, permission has been granted, so I hope to consult with Dr. Klimek as well.

Trust me, there are days that I hate the uncertainty, days that I hate the destruction, days that I hate the mysteriousness, days that I hate the wonderment and yes, there are days, that for a passing moment, I am mad as hell! I have been deprived of so much and have lost so much time. However, I have been told not to ask the infamous "Why me?" question, but to instead ask myself "Why not me?" I am no better or any different than any other human being. I sometimes believe I have been given what I can handle. So, as of now, I continue to wait for new decisions to be made. I do not know where my path may lead or how the road may curve or bend, but I do know I must continue to "Walk On." I do know that not solely, but

collectively, we must continue to raise awareness levels. As a start, I have become a patient partner in the "Running for Rare Diseases" program that increases awareness levels of rare diseases and promotes diagnosis for patients. This program was founded by a group of employees at Genzyme in partnership with the National Organization for Rare Disorders (NORD). The group established the "Running for Rare Diseases Marathon Team" made up of primarily Genzyme Employees. Each runner is then paired up with a patient partner who is battling a rare disease. The runners spend countless hours training to participate in the Boston Marathon and also hosting fundraising events. I am hopeful that a program of this type will be created for the NYC 2015 Marathon. Additionally, Janna Pelle, a Brooklyn-based musician who lost her father to MDS, released an album titled, "The Show Must Go On" with all proceeds of album sales going to the MDS Foundation towards research. Janna plans on hosting an event in January, 2015 at "The Cutting Room" in New York City to raise awareness levels about MDS. Concurrently, at the same event, she plans to host a bone marrow donor drive as well.

Throughout the years, I have kept a written account of so much that I have gone through. I have shared with others and have listened to stories of isolation, desolation, ruination, despair, anxiety, yet have also heard tales of bravery, determination, courage, perseverance, fearlessness, heroism, inspiration, hope, and the list can

**I am hopeful that doctors,
researchers and scientists
will continue their quest
to answer so many of the
many unanswered
questions...**



go on and on. I know first-hand how a rare disease can impact you and your loved ones physically, emotionally, socially, psychologically and financially. A rare disease can absolutely rock your world. The time is ripe for me to share with the world, my journey, in hopes that you will be able to see it through my eyes. I am hopeful that my sharing will help others who are battling a rare disease or maybe someone who is battling a mysterious illness and remains undiagnosed or misdiagnosed. I am hopeful that doctors, researchers and scientists will continue their quest to answer so many of the many unanswered questions. I am hopeful that one day, pharmaceutical companies will one day discover a magical drug that will not only help with managing day-to-day symptoms but instead be curative for one of us. I am hopeful that more rare disease patients will be considered for either stem cell or bone marrow transplants, as this is an area that holds so much promise. I am hopeful that one day, I will be the real me once again.

Years ago, I was presented with a dove pendant necklace for my birthday. Upon presentation, I was told, "Don't worry, Aunt Tazie, one day you'll be set free." Every time I think of those words, the tears well up in my eyes. I continue to patiently wait for that day to come. My name is Tara Dove Notrica, and each day, I continue to not only battle Mast Cell Disease but possibly MDS as well. This is my story!

SPECIAL ANNOUNCEMENT



YALE

Present

My Last Christmas

A Christmas movie about love, faith, family, and dealing with MDS.

OUR CAST



Dean Cain
(Lois & Clark:
The New Adventures
of Superman)



Quinton Aaron
(The Blind Side)



Q Parker
(112)



Shad Gaspard
(WWE)

PLOT OUTLINE

At 17 years old, Angelica suffers from Myelodysplastic Syndromes (MDS) and receives regular chemotherapy as treatment. With her parents struggling with cancelled health insurance and her health declining, Angelica's life depends on a bone marrow transplant. The search for such a donor is exceedingly difficult, however she needs a multiracial donor, making the search nearly impossible. Despite her severe condition, she finds friendship and love in 17 year old homeless runaway Sean. Together they witness a miracle proving that God works in mysterious ways. In this heartwarming Christmas film, Angelica will ultimately experience a love deeper than she could have ever expected.

We are thrilled to be in partnership with the MDS Foundation, to whom we are donating 5% of this campaign's donations, and 5% of the film's proceeds!

We need **YOUR** help!

We need your help to make this film happen. Conventional financing for many films comes to fruition based on genres that are viewed as promisingly "profitable", "bankable", and "moneymaking" by distributors and sponsors. This includes genres such as horror, thriller, action, etc. My Last Christmas, a drama based on MDS, cancer, and awareness, does not fall under this category. It is for this reason that we are asking for your help through indiegogo to make this very important film! For more information, or if you would like to contribute to the production of this movie, please go to: ow.ly/C1AEg



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

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

Access
www.clinicaltrials.gov
for additional information.

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

ANNOUNCING NEW CLINICAL TRIALS

NAME OF INSTITUTION:

Novartis Pharmaceuticals

TRIAL NUMBER:

NCT00940602

Title of Trial or Description:

Myelodysplastic Syndromes (MDS) Event Free Survival With Iron Chelation Therapy Study (TELESTO)

A Multi-center, Randomized, Double-blind, Placebo-controlled Clinical Trial of Deferasirox in Patients With Myelodysplastic Syndromes (Low/Int-1 Risk) and Transfusional Iron Overload.

NOVARTIS

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.

ELI LILLY

disease (very low, low, and intermediate risk) will be studied. The study treatment is expected to last about 6 months for each participant.

Contact the Lilly Clinical Trials Hotline at 1-877-CTLILLY (1-877-285-4559) or 1-317-615-4559 Mon - Fri 9 am-5 pm Eastern time or go to www.clinicaltrials.gov for additional information and to view the active sites.

MIRATI

Vidaza® (azacitidine) compared to Vidaza alone. As a secondary objective, various measures of efficacy will be assessed.

For inclusion, subjects must have a diagnosis of intermediate or high-risk MDS and have not yet been treated with drugs like Vidaza or Dacogen® (decitabine).

Contact Mirati Therapeutics at 858-332-3410 or go to www.clinicaltrials.gov for additional information and to view the active sites.

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:

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Pioneering science delivers vital medicines™



THE MDS FOUNDATION – CELEBRATING 20 YEARS



20th anniversary

the myelodysplastic syndromes foundation, inc.



Dear Friends,

The MDS Foundation is celebrating its 20th year of providing global support and educational services to patients and caregivers living with MDS; as well as healthcare professionals and researchers working daily in the field of MDS. With strong programs and a variety of educational resources, we believe that we enhance the quality of life for our patient population and greatly assist the healthcare professionals who actively treat them.

To celebrate our 20th anniversary, we are asking that you consider supporting us with a donation of \$20.

Founded in 1994, The MDS Foundation continues to be the only international, US-based foundation dedicated solely to MDS. Our Foundation was established by world-renowned researchers dedicated to furthering scientific knowledge, patient support, and education in the myelodysplastic syndromes. These researchers still work very closely with the Foundation, 20 years later, to continue and enhance these efforts.

We ask you to support our Foundation in a special way this year, in celebration of our 20 years of dedicated service to the MDS community.

Please think of the MDS Foundation in your holiday giving this year and make a tax-deductible donation today. Kindly use the return envelope included in this newsletter for your convenience or go to www.mds-foundation.org to make your donation.

Thank you for helping
us make a difference!



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Honor or memorialize your loved one at: www.mds.foundation.org/donate or
contact us at 800-MDS-0839 (within US), 609-298-1035 (Outside US).

ARE YOU DIAGNOSING MDS?

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**Transplant was Liz's cure for MDS.
Can it be yours?**

Liz, a breast cancer survivor, was diagnosed with MDS in 2007. She received a transplant in 2008 and now enjoys spending time outdoors—gardening and hiking.

Be The Match® provides support and resources for patients with myelodysplastic syndrome (MDS). We have a team dedicated to supporting patients, caregivers and families before, during and after transplant.

For Clinicians: BeTheMatchClinical.org For Patients: BeTheMatch.org/patient

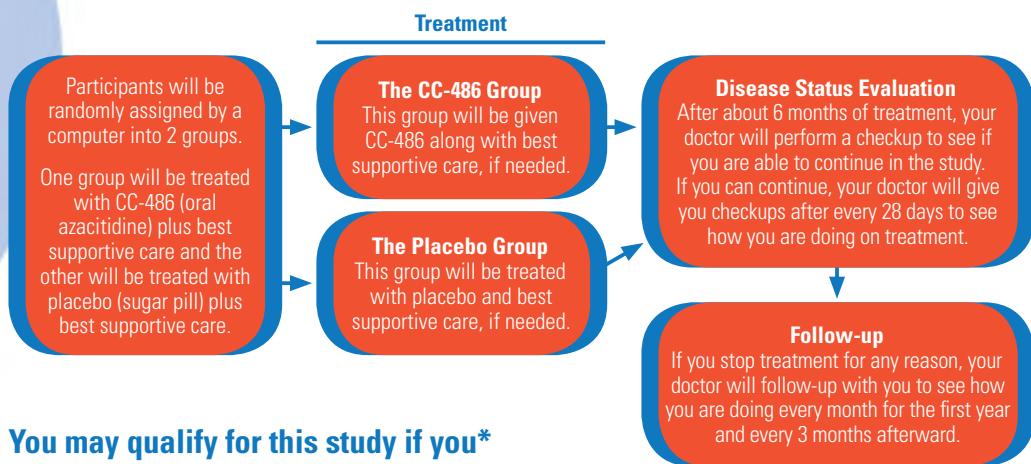


Do you have myelodysplastic syndromes (MDS)? You may be eligible for this clinical study

Announcing the QUAZAR Lower-Risk MDS Study

QUAZAR Lower-Risk MDS is a study for people with MDS who need blood transfusions due to low red blood cell counts (called anemia) and low platelet counts (called thrombocytopenia).

The QUAZAR MDS Study



You may qualify for this study if you*

- Are age 18 years or older
- Have been diagnosed with MDS
- Have low red blood cell counts and are dependent on blood transfusions
- Have low blood platelet counts

You may not be eligible for this study if you*

- Have had previous stem cell transplants
- Have been treated with VIDAZA® (azacitidine for injection) or DACOGEN® (decitabine for injection)

For more information about this study

- Call 646-307-8079 or toll-free at 866-743-9791
- E-mail QuazarMDSstudy@emergingmed.com
- Scan the QR code



* Additional criteria apply.

DACOGEN is a registered trademark of Eisai Inc. and Janssen Pharmaceuticals, Inc.

VIDAZA is a registered trademark of Celgene Corporation.



Connect® MDS and AML: The Myelodysplastic Syndromes (MDS) and Acute Myeloid Leukemia (AML) Disease Registry

Celgene is researching the following objectives in MDS and AML patient populations:

- Current and evolving patterns for diagnosing, treating, and monitoring patients
- Outcome measures
- How routine practice compares to national treatment guidelines
- Treatment patterns and outcomes in patients with del(5q), with or without additional cytogenetic abnormalities
- Association of patient characteristics, treatment regimens and clinical outcomes with patient-reported Health Related Quality of Life (HRQoL) and economic outcomes
- Clinical outcomes based on treatment in patients with or without mutations
- Correlation between mutation detection/allele burden in bone marrow and peripheral blood samples
- Molecular and/or cellular marker's relation to prognostic classification, drug mechanism of action and clinical and treatment outcomes

Select eligibility criteria:

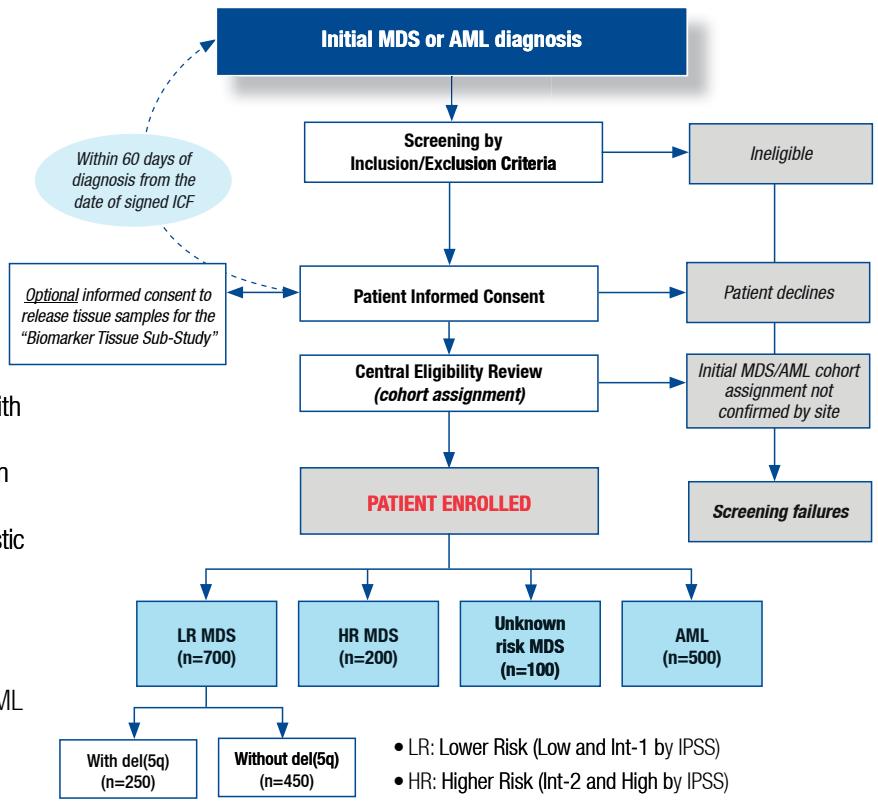
- Newly diagnosed,* primary or secondary MDS or AML
- MDS patients must be at least 18 years
- AML patients must be at least 55 years of age
- Patients must be willing and able to complete enrollment and follow-up HRQoL instruments, for which patients must be proficient in either English or Spanish

*To be considered “newly diagnosed,” a patient’s confirmed diagnosis must be made up to 60 days prior to the date of ICF signature.

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 or AML patients per quarter



- LR: Lower Risk (Low and Int-1 by IPSS)
- HR: Higher Risk (Int-2 and High by IPSS)
- MDS patients of unknown risk must have undergone two unsuccessful bone marrow cytogenetic testing attempts
- APL diagnosis is excluded.

To learn more about this MDS/AML Disease Registry Study, contact:
connectmdsaml-registry@celgene.com
(ClinicalTrials.gov Identifier: NCT01688011)





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One source, many possibilities®

HAVE YOU OR SOMEONE YOU KNOW BEEN DIAGNOSED WITH MYELODYSPLASTIC SYNDROMES (MDS)?

ANNOUNCING A CLINICAL RESEARCH TRIAL

Pharmacokinetic Guided Dose Escalation and Dose Confirmation
With Oral Decitabine and Oral CDAi in Patients With MDS

ABOUT THE STUDY

ASTX727 is an oral dose combination investigational drug, of oral decitabine + E7727, an inhibitor of the metabolism of decitabine. Intravenous decitabine is one of the approved drugs by the FDA for this use. The trial is designed to define the doses of both drugs so that the blood levels of decitabine after oral administration look like what is seen with IV decitabine.

ELIGIBILITY

- Ages Eligible for Study: 18 Years and older
- Genders Eligible for Study: Both
- Accepts Healthy Volunteers: No

CRITERIA

Inclusion Criteria:

- IPSS low, intermediate -1, intermediate-2, or high risk MDS (including CMML) in Dose Escalation and Dose Confirmation-Randomization; only intermediate-2, or high risk MDS in Dose Confirmation-Open Label
- ECOG 0 to 2
- No major surgery within 2 weeks of starting study treatment
- No cytotoxic chemotherapy within 2 weeks of starting study treatment
- Able to swallow pills

Exclusion Criteria:

- Previous treatment with 2 or more courses of decitabine (all stages) or azacitidine (Dose Confirmation stage only)
- Treatment with investigational therapy within 2 weeks of study treatment
- Uncontrolled medical disease(s) or active, uncontrolled infection
- Diagnosed with AML
- Active uncontrolled gastric or duodenal ulcer
- Known history of HIV or hepatitis C or B

Clinicaltrials.gov Identifier #: ASTX727-01

Patient enrollment needed. For more information please call 1-800-MDS-0839
(Outside the US: 609-298-1035) or visit www.mds-foundation.org



BLAST MDS Trial

Birinapant pLus Azacitidine Study in the Treatment of MDS

THE BLAST MDS TRIAL FOR PATIENTS WITH HIGHER RISK MDS IS ACTIVELY ENROLLING!

WHAT is the BLAST MDS Trial?

A clinical research study sponsored by TetraLogic Pharmaceutical Corporation. This is a study of azacitidine with and without the experimental drug birinapant(TL32711) in higher risk MDS or CMML patients.

WHY is this study being done?

- This study is being done to see if an experimental drug will produce an enhanced response in certain patients when added to the approved drug azacitidine for patients with higher risk MDS

WHAT are the key goals of the study?

The goal of this study is to learn if there is an indication that the two drugs together may:

- Increase the number of patients who respond compared to the approved drug alone and increase the duration of that response
- Increase a patient's overall survival
- Delay the time to progression to AML
- Increase the chances of certain patients being eligible to receive a bone marrow transplant
- Reduce some patients need for so many blood transfusions
- Provide information on the side effects of the co-administered combination compared to the approved drug alone

Some of the requirements to enroll in the study include:

- Patients with a confirmed diagnosis of MDS/CMML
- IPSS score of intermediate 2 or High
- ECOG performance status of 0 or 1
- NO prior treatment with hypomethylating agents for MDS/CMML



If you are a physician or health care provider and would like to refer a patient for enrollment into this clinical trial OR you are an MDS patient who is newly diagnosed with MDS and are interested in learning more about the clinical research study, please visit ►►►

ClinicalTrials.gov:
[http://clinicaltrials.gov/ct2/show/
NCT02147873](http://clinicaltrials.gov/ct2/show/NCT02147873)

You may also learn more about TetraLogic's ongoing Phase Ib/2a dose escalation trial for patients with higher risk MDS by visiting ClinicalTrials.gov: <http://clinicaltrials.gov/ct2/show/NCT01828346>

THE 13TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES



Advancing Research & Patient Care

THE 13TH INTERNATIONAL SYMPOSIUM ON **MYELODYSPLASTIC SYNDROMES**

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

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MDS



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