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mds news

newsletter of the myelodysplastic syndromes foundation

MDS NEWS HIGHLIGHTS

FROM THE GUEST EDITOR'S DESK

- **Cord Blood Transplantation for the Treatment of Myelodysplastic Syndromes**

Presented by *Juliet N. Barker, MBBS (Hons), FRACP*
Memorial Sloan-Kettering Cancer Center

ASH 2014 MDS FOUNDATION BREAKFAST SYMPOSIUM

December 5, 2014 • San Francisco, California

- **PLAN TO ATTEND!**

IN THIS ISSUE

www.mds-foundation.org

GUEST EDITORIAL

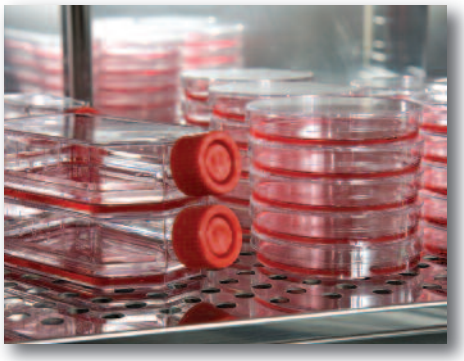
Cord Blood Transplantation for the Treatment of Myelodysplastic Syndromes

Dr. Juliet N. Barker
Associate Attending,
Adult Bone Marrow Transplant Service Director
Cord Blood Transplantation Program
Memorial Sloan-Kettering Cancer Center

Cord blood transplantation (CBT) has achieved disease-free survival comparable to that of volunteer donor transplants in children and adults with acute leukemia...

Cord blood is a rich source of blood-forming stem cells collected from healthy newborns. Cord blood that is cryo-preserved in public banks in both the United States and abroad (predominantly Europe) has the advantage of rapid availability. This is important for patients with acute leukemia or myelodysplastic syndromes (MDS) in need of urgent transplantation but without a readily available sibling or unrelated volunteer donor. Furthermore, the naïve immune system conferred by the neonatal donor results in a reduced stringency of required tissue type (known as human leukocyte antigen or HLA) match between the patient and the donor. Cord blood can, therefore, extend transplant access to potentially curative transplant therapy to patients in need of donor (or allogeneic) transplantation but without suitable adult donors. This frequently includes patients of non-European or part non-European ancestries (eg, patients with African, Asian or Hispanic origins) as well as other patient groups such as those originating from southern Europe. Cord blood is routinely used as an alternative stem cell source for patients with hematologic malignancies and at Memorial Sloan-Kettering Cancer Center (MSKCC) cord blood transplantation (CBT) has achieved disease-free survival comparable to that of volunteer donor transplants in children and adults with acute leukemia.

In patients with MDS, CBT may be appropriate for selected patients with high risk disease, although to date CBT has most commonly been investigated once the disease has evolved to acute leukemia. In this setting, it has the great advantage of a strong graft-versus leukemia effect that can protect the patient from relapse after transplantation. Challenges to successful cord blood transplantation in MDS patients remain, however. Transplantation after high doses of chemotherapy and radiation can have prohibitive toxic side effects in many adult patients. However, cord blood transplantation involving only low doses of chemo-radiation are associated with an increased risk that the patient's immune system will reject the transplanted cells or that the MDS will relapse. MSKCC has developed a novel transplant regimen of intermediate intensity that has been successful in young and middle aged patients with high-risk acute leukemia and MDS with a two-year disease-free survival of 64%. Challenges remain, however in the application of cord blood transplantation in patients over the age of 60 and those with other serious co-existing diseases in addition to MDS that can make transplant therapy more difficult to tolerate. New strategies to improve CBT to further optimize the success rate and quality of life after transplant are under investigation and offer the chance of cure in patients with high-risk MDS.

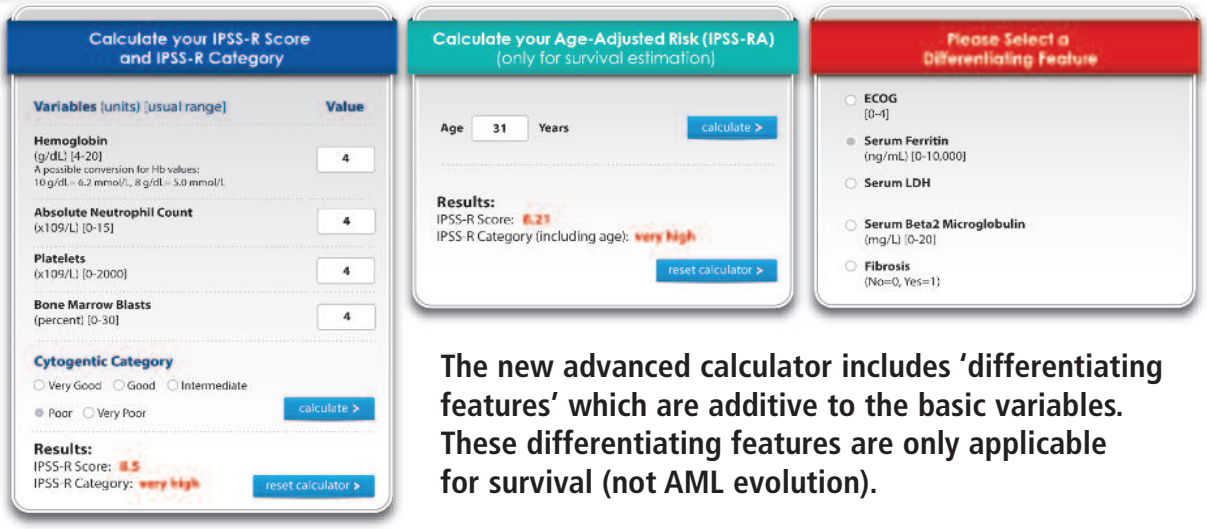


New strategies to improve CBT to further optimize the success rate and quality of life after transplant are under investigation and offer the chance of cure in patients with high-risk MDS.

INTERNATIONAL PROGNOSTIC SCORING

new

ADVANCED IPSS-R CALCULATOR TOOL



The new advanced calculator includes 'differentiating features' which are additive to the basic variables. These differentiating features are only applicable for survival (not AML evolution).

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

You can access both calculators by going to:
www.mds-foundation.org/ipss-r

IWG-PM
INTERNATIONAL WORKING GROUP FOR THE PROGNOSIS OF MDS

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. Preliminary review suggests that such analysis should provide a useful resource for the diagnosis, sub-classification and prognosis of these patients. In addition, the generation of 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.

TECH IT OUT AND DOWNLOAD OUR FREE APP!

Look for the **IPSS-R Calculator** on the iPhone and Android App Store

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

Current Therapeutic and Biologic Advances in MDS

Friday, December 5, 2014
7:00–11:00 am

San Francisco, California
Moscone Center

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 (MDS).

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 some newer condition 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

AGENDA

7:30 am – 7:40 am
Program Overview and Objectives
Peter Greenberg

7:40 am – 8:15 am
Update of WHO and Molecular Classifications in MDS
Mario Cazzola

8:15 am – 8:50 am
Therapeutic and Prognostic Role of Epigenetic Abnormalities in MDS
Stephen Nimer

PROGRAM OVERVIEW

Recent developments in clinical classification, epigenetic treatment and hematopoietic stem cell transplantation have generated valuable advances for aiding management of patients with myelodysplastic syndromes (MDS). Determining the impact of patient comorbidity and quality of life inform the use of these therapeutic approaches. These issues will be discussed as well as recent biologic data describing the role of altered marrow microenvironmental innate immunity involved in improved understanding of pathogenetic lesions underlying this disease.

8:50 am – 9:25 am
Current Results of Alternative Conditioning Regimens and Donors for Allogeneic Hematopoietic Stem Cell Transplantation in MDS
Joachim Deeg

9:25 am – 10:00 am
Impact of Comorbidity on Quality of Life and Clinical Outcomes in MDS
Peter Valent

10:00 am – 10:35 am
Myeloid-derived Suppressor Cells and Altered Innate Immunity Contribution to MDS Pathogenesis
Alan List

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

FACULTY

Mario Cazzola, MD
University of Pavia Medical School
Pavia, Italy

H. Joachim Deeg, MD
Fred Hutchinson Cancer Research Center
Seattle, Washington

Peter Greenberg, MD
Stanford University
Medical Center
Stanford, California

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

Stephen D. Nimer, MD
Sylvester Comprehensive Cancer Center
Miami, Florida

Peter Valent, MD
University of Vienna
Vienna, Austria

VISIT THE MDS FOUNDATION
BOOTH #3040


mds foundation
the myelodysplastic syndromes foundation, inc.
Advancing Research & Patient Care
THE 13TH INTERNATIONAL SYMPOSIUM ON
MYELODYSPLASTIC SYNDROMES
Washington, D.C., U.S.A.
APRIL 29 - MAY 2, 2015
MDS2015

Symposium Chairman:
Steven D. Gore, MD Director of Hematologic Malignancies,
Yale University School of Medicine, New Haven, CT, USA

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

THE MDS 2015 PROGRAM INCLUDES A TRAINEES PROGRAM, NURSING PROGRAM, PATIENT FORUM, DEBATES, CASE-BASED DISCUSSIONS, TOPICAL WORKSHOPS, ORAL AND POSTER PRESENTATIONS ON THE FOLLOWING TOPICS:

- Epigenetics and epigenomics
- Splicing factors
- Preclinical and mouse models
- MDS predisposition
- Innate immunity and bone marrow failure states
- MDS and the aging stem cell
- Epidemiology and outcomes
- Microenvironment
- Biology of disease progression
- Clinical

www.kenes.com/mds

Follow us on:

INTERNATIONAL EVENT SPOTLIGHT

JOIN US IN MILAN, ITALY ▪ FRIDAY, JUNE 13, 2014

MDS Patients & Caregivers LIVING With MDS Forum…

What you get at an MDSF Patients & Caregivers LIVING with MDS Forum

- ***Education***
  Get up-to-date, vital information.
- ***Access to Experts***
  Get one-on-one access to the experts with time to ask questions about your treatment options.
- ***Camaraderie***
  Share your experiences and gain strength from others in the MDS community.

MILAN MDS FORUM

Don't Miss Out on this FREE EVENT – REGISTER TODAY

Italian MDS Patients and Caregivers LIVING with MDS Forum

DATE: FRIDAY, 13 JUNE 2014
10.00–14.00

LOCATION:

Best Western Hotel Madison Milan
20124 Milano – Via Gasparotto, 8
Manhattan Conference Room

GUEST SPEAKERS:

Dr. Valeria Santini
Nurse Claudia Boglione
University of Florence
Azienda OSP Carieggi, Florence, Italy

Francesca Tognetti, *AIL*

REGISTER:

ailpazienti@ail.it or call 06/70386012

Complimentary breakfast and lunch.

mds foundation
the myelodysplastic syndromes foundation, inc.

AIL
ASSOCIAZIONE ITALIANA CONTRO LE LEUCEMIE-LINFOMI E MIELOMA
ONLUS

Don't delay. To find out more or to register for the event, just call or email today – See you in Milan!

MILAN, ITALY ▪ JUNE 12–15, 2014

EHA | EUROPEAN HEMATOLOGY ASSOCIATION

MARK YOUR CALENDAR: VISIT THE MDS FOUNDATION BOOTH #132

HERE IS A LINK TO THE MILAN EHA CONGRESS:
http://www.ehaweb.org/congress-and-events/annual-congress/19th-congress/key-information

EUROPEAN HEMATOLOGY ASSOCIATION

MEET THE MDS EXPERTS

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

INTRODUCING...

Peter L. Greenberg

Medical Specialty: Hematology, Internal Medicine
Medical School: George Washington School of Medicine
Residency: Barnes Hospital, Washington University **Board Certification:** Hematology, Internal Medicine

What led you to the medical field? *Excitement about biology, wish to be useful.*

What interested you in hematology/myelodysplastic syndromes in general?
Puzzle solving about the regulation of blood cell production challenged me to choose hematology. MDS was/is an important illness to try to understand and prevent disease progression to a more aggressive stage.

What is the most gratifying part of your job? *Interacting with patients.*

Sandra E. Kurtin, RN, MS, AOCN, ANP-C
The University of Arizona Cancer Center, Tucson, Arizona

INTRODUCING...

Sandra E. Kurtin

Medical Specialty: Hematology/Oncology
Nursing School: The University of Arizona, Tucson, Arizona
Board Certification: American Academy of Nurses Adult Nurse Practitioner, Oncology Nursing Society, Advanced Oncology Certification

What led you to the medical field? *Enjoy working with older adults.*

What interested you in hematology/myelodysplastic syndromes in general?
The rapid rate of scientific discovery, the patient population, and inspiring colleagues.

What is the most gratifying part of your job? *Taking part in development of new therapies, bringing those new therapies or clinical management strategies to the patient, and helping patients and their caregivers to LIVE while surviving with their cancer diagnosis.*

Charlotte Niemeyer, MD
University Children's Hospital Freiburg, Germany

INTRODUCING...

Charlotte Niemeyer

Medical Specialty: Pediatric Hematology and Oncology
Medical School: University Notthingham, Great Britain; University Kiel, Germany
Residency: University Kiel, Germany **Board Certification:** University Freiburg, Germany

What led you to the medical field? *Curiosity and interest in people!*

What interested you in hematology/myelodysplastic syndromes in general?
I love red cells and looking through the microscope. It's a great field with lots of biology!

What is the most gratifying part of your job? *To cure children.*

ABOUT THE FOUNDATION

Who Are We?

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

What is MDS?

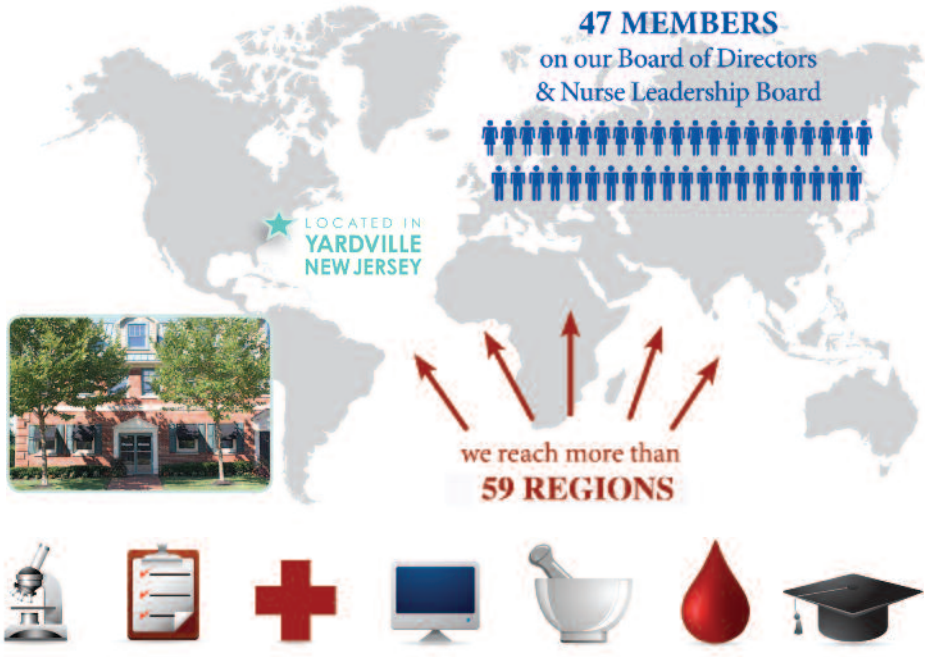
The myelodysplastic syndromes are a group of bone marrow disorders resulting in the ineffective production of normal mature blood cells. Many patients experience anemia from the lack of effective red blood cells, thereby requiring frequent blood transfusions. A shortage of white blood cells may cause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

What We Do

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

Where We Are

The Foundation is located in Yardville, New Jersey and is active in more than 59 regions around the world. Our Board of Directors consists of physicians and nurses actively engaged in searching for a cure of the disease. Our Nurse Leadership Board is comprised of specialized nurses sharing information and teaching others how to care for MDS patients. Together, the Board of Directors and the Nurse Leadership Board consist of 47 members representing 14 countries. Please see our website www.mds-foundation.org for a complete list of our board members and other vital information about the disease and the Foundation.



Our Fundraising Efforts

As a tax exempt non-profit, section 501(c)3 organization, donations to the MDS Foundation qualify for a U.S. tax deduction (it is essential to consult with your tax advisor to confirm your own tax situation).

The MDS Foundation actively seeks financial support for our mission and programs to continue providing services such as the following:

- International Working Group for Prognosis in MDS (IWG-PM)
- Young Investigator Research Grants
- Hot-line for patients and caregivers to speak with our Patient Liaison at 800-MDS-0839
- Numerous Face to Face Patient Forums in multiple cities with presentations by local physicians
- Online Patient Forum monitored by experts
- Designation of Centers of Excellence (COE) meeting the highest standards for diagnosis, treatment, and patient care
- Patient Referrals to COEs
- *Building Blocks of Hope*© handbook (in print or online) with complete written and video information on the care and treatment of MDS
- The MDS News Email Alerts
- Biennial International MDS Symposia for professionals & continuing medical and nursing education programs

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

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

www.mds-foundation.org

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

Building Blocks of Hope™

Strategies for Patients and Caregivers LIVING with MDS

The **BUILDING BLOCKS OF HOPE** is a global print and online patient advocacy initiative, providing a personalized educational program for the patient and caregiver to prepare, participate, and **LIVE** with MDS.

The digital book is quite striking and easy to read online. You can also download the PDF file for printing. Please use the following link to access both formats:

www.mds-foundation.org/bboh.

We will be working with the MDS Foundation Board of Directors, International Nurse Leadership Board (MDSF-NLB) and colleagues from our MDS Centers of Excellence to translate and adapt the Building Blocks of Hope (BBoH) into multiple languages in order to reach as many MDS patients as possible. The BBoH is now available in German and French Canadian. There is also a Canadian adaptation that is available on our website at www.mds-foundation.org. We are currently translating the BBoH into Armenian, Danish, Dutch, French, Italian, Spanish and Turkish. We are also adapting the English version for MDS patients in Australia. Once these translations are complete they will be added to our website.

The online versions of the BBoH will be accessible to you at any time, and the PDF format can be downloaded for local use. Although these pages are copyrighted, we extend an invitation to print and distribute individual pages, without modification, as needed to support patients and caregivers **LIVING** with MDS!

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

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

– Steve Siehr

A PRINT AND ONLINE EDUCATIONAL TOOL

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

The German and French Canadian translations as well as the Canadian adaptation are available now. Translations in French and Spanish coming soon!

THE MDS ACADEMY
AN INTERACTIVE PROFESSIONAL EDUCATIONAL PROGRAM

IT HAS ARRIVED

Practical Tools for Clinical Management of MDS

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

For more information and the complete set of tools go to:

www.mds-foundation.org/clinical-toolbox

MDS FOUNDATION INTERNATIONAL NURSE LEADERSHIP BOARD REPRESENTED AT THE FIRST ANNUAL JADPRO-LIVE SYMPOSIA

The *Journal of the Advanced Practitioner in Oncology* (*JADPRO*) was launched 3 years ago. The mission of *JADPRO* is to improve the quality of care for patients with cancer, support critical issues in advanced practice in oncology and recognize the expanding contributions of advanced practitioners in oncology. In January 2014, nearly 300 advanced practitioners assembled at the first annual *JADPRO* Live meeting in St. Petersburg, Florida. Representatives of the American Society of Clinical Oncology (ASCO), the American Society of Hematology (ASH), the American Society for Radiation Oncologists (ASTRO), and the National Comprehensive Cancer Network (NCCN) offered their perspectives on the role of advanced practitioners (APs) in oncology in the interdisciplinary care of patients with cancer during a roundtable panel discussion moderated by *JADPRO* Editor in-Chief Pamela Hallquist Viale, RN, MS, CNS, ANP. The remainder of the meeting provided collaborative practice presentations with physicians and advanced practitioners providing clinical updates on a number of topics, a poster session, and a number of sessions focused on relevant practice challenges. At the close of the meeting, the Co-chairs of the meeting announced the formation of a new organization, the Advanced Practitioner Society for Hematology and Oncology (APSHO). The *Journal of the Advanced Practitioner in Oncology* (*JADPRO*) will be the Society's official journal and will continue to offer relevant and high-quality articles focusing on the needs of the advanced practitioner (AP) in today's clinical arena. Society members will include advanced practice professionals specializing in oncology, including nurse practitioners (NPs), physician assistants (PAs), clinical nurse specialists, pharmacists, and others.

Three members of the International Nurse Leadership Board for the MDS Foundation were in attendance at the meeting, each of them presenting a poster on topics specific to MDS. Sandra Kurtin, RN, MS, AOCN, ANP-C was a Co-chair for the meeting, founding member of the Board of APSHO, and will serve as Treasurer for APSHO in the first year. Sara Tinsley, ARNP, MS, AOCN, and Jean Ridgeway, MSN, APN, NP-C, AOCN, attended the meeting and presented posters on behalf of the Nurse Leadership Board. The abstracts are included here. The posters in PDF format can be viewed on the MDS Foundation website.

JL12. Management of Lenalidomide-Associated Cytopenias in Myelodysplastic Syndromes: Practical Take-Aways From Clinical Trials

Sandra E. Kurtin, RN, MS, AOCN®, ANP-C, University of Arizona Cancer Center, Tucson; Jean A. Ridgeway, MSN, APN, NP-C, AOCN®, University of Chicago Medical Center, Chicago; Sara Tinsley, ARNP, MS, AOCN®, H. Lee Moffitt Cancer Center and Research Institute, Tampa, on behalf of the MDS Foundation International Nurse Leadership Board

ABSTRACT: Lenalidomide (LEN) is an oral immunomodulatory medication approved for the treatment of patients with transfusion-dependent anemia due to low- or intermediate-1–risk myelodysplastic syndromes (MDS) with del(5q). In clinical trials of LEN in MDS, neutropenia and thrombocytopenia were common; severe myelosuppression was generally managed with dose modifications rather than discontinuations, similar to our clinical experience. If treatment is discontinued too early, patients may not receive enough medication to decrease transfusion needs. Additionally, we have observed patients with sustained, mild-to-moderate, asymptomatic cytopenias that do not need intervention. This is unlike other malignancies in which neutropenia and thrombocytopenia are significant events requiring treatment discontinuation. Therefore, it is important to anticipate and manage LEN-associated cytopenias to extend treatment and optimize outcomes. In this report, MDS-003 and MDS-004 clinical trial data are applied to real-world patient care to illustrate expected cytopenias and outline strategies for practical management of LEN-related cytopenias in MDS patients. Rates, time to onset/recovery, and LEN dose modifications due to neutropenia or thrombocytopenia were examined. These data and expert experience were used to prepare a practical guide for management of cytopenias in LEN-treated MDS patients relevant to advanced practitioners in oncology. Management of cytopenias in LEN-treated MDS patients is dependent on baseline blood counts, bone marrow function, treatment cycle, severity, and symptoms. In the MDS-003/004

trials, rates of grade 3/4 neutropenia and thrombocytopenia were higher in early treatment cycles but decreased thereafter. Severe cytopenias were generally transient and managed primarily with dose reductions and interruptions. A complete blood count (CBC) with differential and platelet count is suggested weekly in the first 8 weeks of treatment when cytopenias are expected and may require temporary dose interruption. LEN should be interrupted and dose reduced for platelet counts <50,000/µL in cycle 1, but in later cycles, platelet counts as low as 30,000/µL are tolerated in the absence of a need for platelet transfusions or bleeding abnormalities. Unlike in other hematologic malignancies, sustained moderate but asymptomatic cytopenias may persist over months or years with continued transfusion independence and no need for dose modification in the absence of symptoms or decreases in quality of life (Kurtin, 2012). Familiarity with expected cytopenias, planning for effective management, and setting expectations for the patient and family will support the advanced practitioner in management of cytopenias and promote continued therapy in the MDS patient achieving transfusion independence in response to LEN.

JL13. Practical Guide to Management of Lenalidomide-Related Rash in Patients With MDS

Sara Tinsley, ARNP, MS, AOCN, H. Lee Moffitt Cancer Center and Research Institute, Tampa; Sandra E. Kurtin, RN, MS, AOCN, ANP-C, University of Arizona Cancer Center, Tucson; Jean A. Ridgeway, MSN, APN, NP-C, AOCN, University of Chicago Medical Center, Chicago, on behalf of the MDS Foundation International Nurse Leadership Board

ABSTRACT: Lenalidomide (LEN) is an oral immunomodulatory medication approved for patients with lower-risk, transfusion-dependent myelodysplastic syndromes (MDS) with del(5q) with or without additional cytogenetic abnormalities. The goal of LEN treatment is to reduce or eliminate red blood cell transfusion dependence. A recent analysis of the Celgene Global Drug Safety database showed that nonserious rash was the leading cause of permanent early discontinuation of LEN in MDS in the postmarketing setting. The majority of discontinuations due to rash occurred in <2 cycles (8 weeks) of treatment. In clinical trials, rash led to no or low rates of discontinuation. LEN rash is generally self-limiting, resolving within 2–3 weeks without adjustment of LEN treatment. This suggests differences in real-world management of rash vs clinical trials. It may take ≥3 cycles of LEN treatment to achieve transfusion benefit. Therefore, early recognition and proper management of rash by advanced practitioners in oncology may reduce morbidity and extend treatment to optimize outcomes of LEN-treated patients with MDS. This practical guide to management of LEN-related rash in patients with MDS encompasses identification of physiology, signs, and symptoms of LEN-related rash, grading of rash, recommended rash management guidelines, and patient communication tips. Most LEN-related rash is mild-to-moderate and may present as patchy, raised, macular skin lesions, sometimes with localized urticaria, which may be associated with pruritus. Cutaneous reactions may be associated with immunomodulatory properties of LEN and usually require no intervention. Patients with mild-to-moderate rash (grade 1/2; covering ≤30% of body surface area [BSA]) may be treated with topical corticosteroids and/or oral antihistamines until it is grade ≤1 or resolves. For grade 3 rash (covering >30% of BSA), interrupting LEN and treating with oral antihistamines or short courses of oral corticosteroids is recommended. LEN treatment can generally be restarted after interruption without rash reoccurrence. LEN must be permanently discontinued for life-threatening rash (grade 4), angioedema, exfoliative or bullous rash, or if Stevens-Johnson syndrome or toxic epidermal necrolysis is suspected. Patients can be further educated using rash photos and explanations of how rash is treated in advance, and encouraged to promptly report signs of skin problems. Advanced practitioners can effectively manage LEN-related rash by being aware of symptoms, applying appropriate levels of intervention, and involving patients in self-reporting early signs of rash through upfront educational initiatives.

JL14. Practical Guide to Bone Marrow Sampling for Suspected Myelodysplastic Syndromes

Jean A. Ridgeway, MSN, APN, NP-C, AOCN, University of Chicago Medical Center, Chicago; Sara Tinsley, ARNP, MS, AOCN, H. Lee Moffitt Cancer Center and Research Institute, Tampa; and Sandra E. Kurtin, RN, MS, AOCN, ANP-C, University of Arizona Cancer Center, Tucson, on behalf of the MDS Foundation International Nurse Leadership Board

ABSTRACT: Over 10,000 individuals are diagnosed with myelodysplastic syndromes (MDS) annually in the United States. Bone marrow (BM) examination is essential for diagnosis, classification, and risk-stratification of MDS. The World Health Organization classification is based on BM blast percentage and type and degree of dysplasia. Risk stratification using the Revised International Prognostic Scoring System requires blasts percentage, depth of cytopenias, and characterization of cytogenetic abnormalities. Proficiency in this procedure is critical to obtain high-quality BM specimens to facilitate accurate diagnoses and minimize patient discomfort and risk. The BM examination requires a BM aspirate (BMA) to evaluate cell morphology and cellular elements, including blasts, and core BM trephine biopsy (BMTB) to describe cellularity, topography, stromal elements, and the proportion and maturation of hematopoietic cells. Combined examination of the BMA and BMTB allows the most thorough morphological assessment. Assessing dysplasia can be difficult, thus specimen quality is critical. Quality depends on the instruments used as well as operator proficiency. Generally, two adjacent sites are sampled to obtain the BMA and BMTB to avoid crush artifact and poor sampling. The posterior iliac crest is the preferred site for this procedure. Patients are positioned prone or in the right/left lateral decubitus position. Following sterile site preparation, the periosteum is infiltrated with 5 to 10 mL of 1% to 2% lidocaine to minimize pain. BMA samples should be evaluated for the presence of spicules to ensure proper BM sampling. If a BMA cannot be obtained due to fibrosis or cellular packing, touch preparation of the BMTB can yield valuable cytologic information. An adequate BMTB specimen must be ≥1.5 cm in length to allow evaluation of ≥10 partially preserved intertrabecular areas. Following the procedure, firm pressure is applied to the site for 5 minutes for adequate hemostasis, followed by placement of a pressure dressing. Patients at risk of bleeding (thrombocytopenia, aspirin use, and anti-coagulation) should be evaluated, and if necessary treated, prior to the procedure to reduce bleeding risk. The patient should be instructed not to bathe, swim, or soak in a Jacuzzi for at least 48 hours after the biopsy. Complications are unusual but patients should be given an emergency contact number in case of bleeding, pain, fever, erythema, or swelling at the biopsy site. The pressure dressing may be removed after 24 hours and acetaminophen may be taken for pain.

QUALITY OF LIFE: HOW DOES IT CHANGE WITH A DIAGNOSIS OF MYELODYSPLASTIC SYNDROMES (MDS)?

Sara Tinsley, ARNP, AOCN
Nurse Practitioner, Malignant Hematology, Moffitt Cancer Center

Many patients with newly diagnosed MDS ask how the diagnosis will change their life, and more importantly their quality of life. What is quality of life? It is a commonly used phrase that is used to describe living a life that is personally meaningful. Each person defines their own quality of life. No one can evaluate another person's quality of life accurately. Health related quality of life (HRQoL) is a concept covering physical, psychological, and social aspects of a person's life, as well as

symptoms caused by an illness and its treatment (Aaronson, 1988). In order to truly answer the question of how MDS changes HRQoL , more research needs to be performed. Early research with HRQol provides insight into symptoms experienced by MDS patients.

Common symptoms for patients with MDS and their impact on QOL were studied by Steensma et. al (2007). Patients (359) with MDS were recruited from the MDS Foundation by internet. From these questionnaires, 65% of patients reported having received blood products at some point following their MDS diagnosis. The most common symptom reported by patients with MDS was excessive fatigue which was mentioned in 89% of surveys. Other problems included bruising/bleeding (55%), night sweats (43%), bone pain (39%), fevers (28%), skin rash (25%), undesired weight loss (25%), and recurrent infections (20%). With this self-report questionnaire, it is difficult to know how long the individuals had been diagnosed, the specific MDS subtype, and whether or not they were receiving treatment.

Psychosocial factors also play a role in HRQol for MDS patients. According to Thomas (2012), uncertainty about MDS diagnosis and treatment negatively impact QOL, with patients reporting receiving limited emotional support and education from the healthcare team. Uncertainty of the disease is a difficult issue for many patients. Building Blocks of Hope developed by Sandy Kurtin and the MDS nurse leadership board is an excellent resource for MDS education and support.

Research continues and patient participation is essential for understanding how MDS affects HRQol. A new MDS specific QOL tool has been developed (Abel, Klaassen et al. 2014), and is being validated at several cancer centers around the world. Regular evaluation of HRQoL in the clinical setting will enhance communication between the patient and healthcare providers. Increased awareness of the areas identified by the patient that negatively impact QOL will assist health care providers to tailor care for patients and improve QOL.

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Thomas, M.L. The impact of myelodysplastic syndromes on quality of life: lessons learned from 70 voices. *Journal of Supportive Oncology*. 2012 Jan–Feb;10(1): 37–44.

ACCESS THIS LINK TO COMPLETE YOUR QUALITY OF LIFE SURVEY:
https://www.surveymonkey.com/s/MDSPatientQoLSurvey

PRACTICE AND TREATMENT SURVEYS

MDS PRACTICE AND TREATMENT SURVEY FOR HEALTHCARE PROFESSIONALS

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

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

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

MDS PATIENT QUALITY OF LIFE SURVEY

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

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

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

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

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

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

Highlights of Latest Literature in MDS

Suneel D. Mundle, PhD
Rhea Mundle

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

EPIDEMIOLOGY AND OUTCOMES RESEARCH:

1. Bammer C et al. Clustering of comorbidities is related to age and sex and impacts clinical outcome in myelodysplastic syndromes. *J Geriatr Oncol*. 2014: Mar 10 [Epub ahead of print]. (http://www.ncbi.nlm.nih.gov/pubmed/24636334)

   Hematopoietic cell transplantation-comorbidity index assessment of 616 MDS patients from Austrian MDS platform showed that cardiovascular disease (~28%), diabetes (~12%) and prior tumor history (~10%) as the most frequent comorbidities which were more preponderant in men and in patients with > 65 years of age. Cardiac arrhythmia and prior solid tumor correlated with shorter overall survival.

2. Kplola Y et al. Evaluation of epidemiological factors in survival of patients with de novo myelodysplastic syndromes. *Cancer Causes Control*. 2014;25(4): 425–435. (http://www.ncbi.nlm.nih.gov/pubmed/24463789)

   The evaluation of 365 de novo MDS cases, showed that Smoking and lifetime occupational agrochemical exposure may play a role in MDS survival.

3. Abel GA et al. Patient reported outcomes for the myelodysplastic syndromes: a new MDS-specific measure of quality of life. *Blood*. 2014;123(3):451–452 (http://www.ncbi.nlm.nih.gov/pubmed/24434998)

   The European Leukemia Net stresses that the role of the Quality of Life (QoL) is vital to treatment and diagnosis for myelodysplastic syndromes (MDS). This letter to editor reports development of a new MDS-specific QOL measure called The Quality of Life in Myelodysplasia Scale version 1 (QUALMS-1), that in an initial evaluation with 32 patient cases ranked fatigue as the most important domain. The tool was further validated in an additional cohort for time to complete as 7.5 mins and to confirm that no question was confusing, unsetting, irrelevant or intrusive. It is now being tested in a larger cohort of 180 patients to confirm its reliability.

TREATMENT:

Iron Chelation:

1. Delforge M et al. Adequate iron chelation therapy for at least 6 months improves survival in transfusion-dependent patients with lower risk myelodysplastic syndromes. *Leuk Res*. 2014: Feb 14 [Epub ahead of print]. (http://www.ncbi.nlm.nih.gov/pubmed/24661630)

   A retrospective study with 127 low/int-1 risk patients from 28 centers in Belgium, showed that for patients adequately chelated for over 6 months had median overall survival of 10.5 years. Mortality increased with transfusion intensity, yet patients adequately chelated over 6 months, had a significantly lower mortality rate (HR= 0.24, p< 0.001).

Growth Factors:

1. Tatarelli C et al. Recombinant human erythropoietin in very elderly patients with myelodysplastic syndromes: results from a retrospective study. *Ann Hematol*. 2014:Mar 20. [Epub ahead of print]. (http://www.ncbi.nlm.nih.gov/pubmed/24647684)

   This study by an Italian cooperative group (GROM) evaluated rHuEPO treatment of patients >80 years old (N= 93, Jan 2002-Dec 2010). While 63% patients received standard dose (40,000 IU/week epoietin alfa or 30,000 IU/week of epoietin beta), 37% patients received a higher dose (80,000 IU/week epoietin alfa).The erythroid response rate was ~63% with no thrombotic event reported. Median survival in responders was 49.3 months as compared to 30.6 months in non-responders.

Demethylating Agents:

1. Imanishi S et al. Constitutive activation of the ATM/BRCA1 prevents DNA-damaged induced apoptosis in 5-azacytidine-resistant cell lines. *Biochem Pharmacol*. 2014; Mar 25 [Epub ahead of print]. (http://www.ncbi.nlm.nih.gov/pubmed/24680865)

   Azacytidine resistant cell lines were established from U937 and HL60 cells with prolonged exposure to clinical concentration of the drug. The resistant cells showed a marked genome wide DNA hypomethylation and also, down-regulation of DNMT3A protein, of the genes involved in pyrimidine metabolism. The drug sensitivity could be restored by inhibition of CTP synthase. In particular, was constitutive activation of DNA damage response pathway in resistant cells in contrast to the parent cells which were drug-sensitive. Inhibition of this pathway also restored drug sensitivity.

2. Prebet T et al. Prolonged administration of azacitidine with or without entinostat for myelodysplastic syndrome and acute myeloid leukemia with myelodysplasia-related changes: results of the US Leukemia Intergroup trial E1905. *J Clin Oncol*. 2014; Mar 24 [Epub ahead of print]. (http://www.ncbi.nlm.nih.gov/pubmed/24663049)

   A phase II open label randomized trial compared Aza alone (50 mg/m2/d × 10 days) vs. Aza + entinostat (4mg/ m^2/d on day 3 and 10). The primary goal was to assess hematologic normalization (CR+PR+ trilineanage HI). Among the 149 patients evaluated (MDS, n=97; AML, n=52). The hematologic normalization rate was 32% with Aza alone vs. 27% in combination with entinostat. Median survival was 18 months with Aza alone vs 13 months with the combination treatment.In addition, the combination showed less demethylation than Aza alone.

3. Tobiasson M et al. Limited clinical efficacy of azacitidine in transfusion-dependent, growth factor-resistant, low- and int-1-risk MDS: Results from the Nordic NMDSG08A phase II trial. *Blood Cancer J*. 2014; Mar 7 [Epub ahead of print] (http://www.ncbi.nlm.nih.gov/pubmed/24608733)

A prospective phase II study with transfusion dependent low/int-1 risk patients, administered Aza at 75mg/m2/d × 5 days in a 28 day cycle for 6 cycles. The non-responders received additional three cycles in combination with 60,000 IU/week epoietin. Of the total 30 patients enrolled, 5 had transfusion independence (TI) after 6 cycles of Aza alone and one had response with the addition of epoietin (Total TI rate- 20%). A total of 10 patients (~33%) discontinued early primarily due to adverse event or death. The authors concluded that TI is attainable with Aza in severely anemic MDS patients but the efficacy is limited, toxicities are high and most responses are of short duration.

4. Tan P et al. Dual epigenetic targeting with panobinostat and azacitidine in acute myeloid leukemia and high risk myelodysplastic syndrome. *Blood Cancer J*. 2014;4:e170 (http://www.ncbi.nlm.nih.gov/pubmed/24413064)

   Thirty nine patient received Aza at 75 mg/m2/d × 5 days in a 28 day cycle along with panobinostat (histone deacetylase inhibitor) starting on day 5 dosed 3 times a week in the 28 day cycle. The MTD for panobinostat was determined in phase Ib as 30 mg with toxicities of fatigue, syncope, hyponatremia and somnolence. In Phase II at MTD for panobinostat with 17 additional patients, overall response was 31% in AML and 50% in MDS with a median survival of 8 and 16 months respectively in the two patient groups.

5. Thépot S et al. Azacitidine in untreated acute myeloid leukemia: a report on 149 patients. *Am J Hematol*. 2014;89(4): 410-416 (http://www.ncbi.nlm.nih.gov/pubmed/24375487)

   Previously untreated cases of AML ineligible for intensive chemotherapy (N=149) in a compassionate patient-named program received Aza for a median of 5 cycles. The overall response (CR+PR+ CR with incomplete recovery) was 27.5% after 3 cycles with a median survival of 9.3 months. The survival was significantly superior in responders vs. non-responders.

ATG:

1. Komrokji RS et al. A phase II multicenter rabbit anti-thymocyte globulin trial in patients with myelodysplastic syndromes identifying a novel model for response prediction. Hematologica. 2014:Jan 31 [Epub ahead of print] (http://www.ncbi.nlm.nih.gov/ pubmed/24488560)

   A non-randomized phase II study evaluated rabit anti-thymocyte globulin (r-ATG) at 2.5 mg/kg/day dose (x 4 daily doses). Of the total of 27 patients, 33% had hematologic improvement with a median duration to response being 75 days and a median duration of response 245 days.

2. Duléry R et al. Anti-tyhmocyte globulin before allogeneic stem cell transplantation for progressive myelodysplastic syndrome: A study from the French Society of Bone Marrow Transplantation and Cellular Therapy. *Biol Blood Marrow Transplant*. 2014;20(5):646-654. (http://www.ncbi.nlm.nih.gov/pubmed/24462982)

   Of the 242 MDS patients who received allo-SCT for progressive disease, 93 received rATG at a median total dose of 5 mg/kg, whereas 149 did not. r-ATG did not have impact on median overall or event-free survival, but it significantly reduced the incidence of grade II-IV graft versus host disease.

PATHOBIOLOGY:

1. Ganan-Gomez I et al. Overexpression of miR-125a in myelodysplastic syndrome CD34+ cells modulates NF-κB. *PLoS One*. 2014;9(4):e93404 (http://www.ncbi.nlm.nih. gov/pubmed/24690917)

   miR-125a has been shown to be overexpressed in MDS bone marrow correlating with poorer overall survival. Furthermore, miR-125a appears to inhibit erythroid differentiation in leukemia and MDS cell lines.

REVIEWS AND PERSPECTIVES:

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

1. Adès L, Itzykson R, and Fenaux P. Myelodysplastic syndromes. *Lancet*. 2014;Mar 20 [Epub ahead of print] (http://www.ncbi.nlm.nih.gov/pubmed/24656536)

2. Machlus KR, Thon JN, and Italiano JE Jr. Interpreting the developmental dance of the megakaryocyte: a review of the cellular and molecular processes mediating platelet formation. *Br J Haematol*. 2014;165(2):227-236 (http:// www.ncbi.nlm.nih.gov/pubmed/24499183)

3. Meers S et al. Management of myelodysplastic syndrome sin adults: guidelines from the Belgian Haematological Society. *Acta Clin Belg*. 2013;68(4):253-262 (http://www.ncbi.nlm.nih.gov/pubmed/24455794)

   The following special issue of Best Practice Res Clin Hematol (ed P Fenaux) is dedicated to myelodysplastic syndromes and provides latest update on multiple topics ranging from Iron overload, allogeneic transplant, EPO and demethylating agents to delving into clinical dilemmas of CMML-myelodysplastic or myeloproliferative or MDS and autoimmune disorders- cause or consequence, etc. The issue also explores pathobiology of MDS with focus on RARS, etiology, 5q abnormalities and other somatic/epigenetic mutations.

4. Fenaux P. Myelodysplastic Syndromes: State of the art pathology, diagnosis and manage-ment *Best Practice Res Clin Hematol.* 2014;26(4):307-444.

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

The MDS Foundation, Inc. Observes RARE DISEASE DAY

To raise MDS awareness at the state level as well as to celebrate Rare Disease Day, the MDS Foundation went to the New Jersey State House with other patient groups on March 13th, 2014. We joined the National Organization for Rare Disorders (NORD) and Rare New Jersey, a working group of patients, patient advocates, and industry groups working together to improve the lives of rare disease patients in New Jersey.

Rare diseases are a public health issue, affecting millions of people around the world. The hope is that Rare Disease Day will increase awareness of MDS and other rare diseases, the special challenges encountered by those affected, and the need for research to develop safe, effective treatments or cures.

The total number of patients in the United States and Europe suffering from a rare disease is estimated at 25 and 30 million, respectively. There are millions more around the globe. Specific orphan drug legislations across the globe have been introduced to stimulate the pharmaceutical industry to further develop and bring much needed rare disease therapies to the market.

Our mission is to ensure the needs of all rare disease patients are considered in future legislative policy and making sure "Every Patient Counts" is a NJ State imperative.

Governor Chris Christie signed a proclamation stating February 28, 2014 as *Rare Disease Day* and our testimony to support AJR54, designating the last day in February as *Rare New Jersey Awareness Day*, was supported by the Assembly

STATE OF NEW JERSEY
EXECUTIVE DEPARTMENT

Proclamation

WHEREAS, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States; and

WHEREAS, while each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and

WHEREAS, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

WHEREAS, according to the Food and Drug Administration, nearly 340 orphan drugs and biologics approved for the treatment of rare diseases help between 11 and 14 million people, but well over 15 million Americans with rare diseases have no treatment specific to their disease; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options and difficulties accessing or being reimbursed for treatment; and

WHEREAS, while some rare diseases, such as "Lou Gehrig's disease" and Huntington's disease, are relatively well known, many others that New Jersey families suffer with are not known at all by the public - so that patients and their families must bear a large share of the burden for raising funds for needed research; and

WHEREAS, the National Organization for Rare Disorders is organizing a nationwide observance of Rare Disease Day on February 28, 2014 when patients, medical professionals, researchers, government officials and companies developing treatments for rare diseases will join together to focus attention on rare diseases as a public health issue;

NOW, THEREFORE, I, CHRIS CHRISTIE, Governor of the State of New Jersey, do hereby proclaim:

FEBRUARY 28, 2014
AS
RARE DISEASE DAY

in New Jersey.

GIVEN, under my hand and the Great Seal of the State of New Jersey, this twenty-fifth day of February in the year two thousand fourteen, the two hundred thirty-eighth year of the Independence of the United States.

Lt. GOVERNOR

GOVERNOR

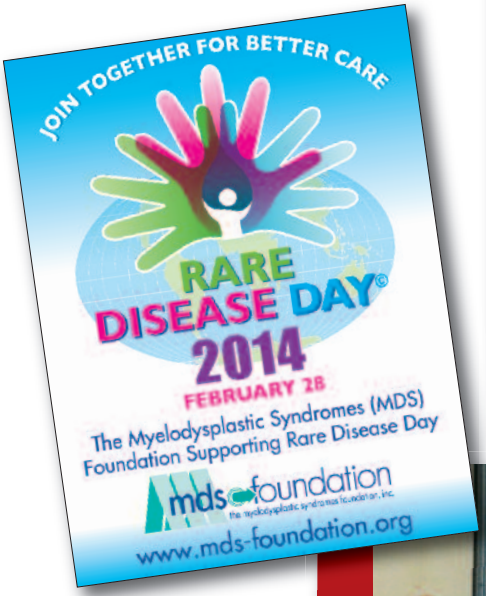
Together, we can raise awareness of rare diseases. Thank you to everyone who supported us and for taking the time to care about rare. We are Jersey Strong!

IRELAND

STANDING STRONG...

FEBRUARY 28, 2014:

MDS Patient Support Groups Around the World Showing Solidarity on RARE DISEASE DAY!



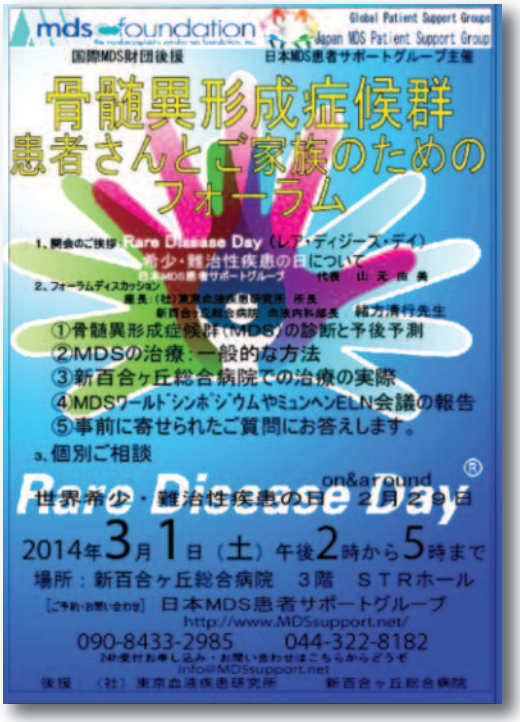
JACKSONVILLE, FLORIDA

SINGAPORE

ALONE WE ARE RARE – TOGETHER WE ARE STRONG!!

2014 RARE DISEASE DAY

JAPAN



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SPREADING THE NEWS WORLDWIDE

MARK YOUR CALENDARS!

PLANNED FUTURE MDS FORUM EVENTS FOR 2014

Don't miss out on these informative, FREE events. REGISTER TODAY!

FREE One-Day Conferences for MDS Patients & Caregivers LIVING with MDS

- February 28 (Rare Disease Day): Jacksonville, FL
- March 29: San Francisco, CA
- April 26: Columbus, OH
- May 23: São Paulo, Brazil
- May 24: Chicago, IL
- June 13: Milan, Italy
- June 21: St. Louis, MO
- July 19: Winston-Salem, NC
- August 2: Minneapolis, MN
- August 16: Scottsdale, AZ
- September 20: New York, NY
- October 11: Houston, TX

Registration is required to attend. Learn the latest on the diagnosis & treatment of MDS from leading experts in the field. Complimentary breakfast & lunch. Call 1-800-637-0839 Ext. 203 or email dmurray@mds-foundation.org for more details and to RSVP.

PLEASE MAKE SURE TO REGULARLY CHECK OUR ONLINE EVENTS CALENDAR
http://www.mds-foundation.org/events
and FACEBOOK FOR OUR FREE MEETINGS TAKING PLACE IN A CITY NEAR YOU!

MDS FOUNDATION STORE

NEW MDS AWARENESS ITEMS AVAILABLE!

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

3 WAYS TO ORDER:

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

Raising awareness is a year-round job!

Thank you for your support.

PEOPLE HELPING PEOPLE...
Established MDS Patient Support Groups

United States

- **Chicago, Illinois MDS Support Group**: Meets on the fourth Tuesday of the month from 1:30–3:00 pm at Northwest Community Hospital's Cancer Service department (lower level), 800 W. Central Road, Arlington Heights, Illinois. Contact Kim Jensen at kjensen@nch.org or call: 847-618-6914.
- **Lakeland, Florida Regional MDS Support Group:** For more information call Vivian Paul at 863-698-5137 or Kathe Dempster at 863-816-8482.
- **New York, New York MDS Support Group**: Contact the group facilitator, Lisa Tomcykoski at drtomcykoski@yahoo.com for further details.
- **Central Pennsylvania MDS Support Group:** For more information call Charlie Ryder at 717-766-0811, email charlieryder503@gmail.com.
- **Puget Sound MDS Support Group:** For more information call Janine Kowack at 206-992-0609 or email jkowack@ comcast.net.
- **Southern California MDS Support Group**: Meets on the third Saturday of the month at St. Mary Star of the Sea Church, 609 Pier View Way, Oceanside, CA 92054 at 2:30 PM. Contact Susan Pope at smpopes@gmail.com or call: 760-744-7665.
- **Stanford Cancer Center MDS Patient & Family Support Group:** Meets the first Friday of the month from 1:30–3:00 pm at the Stanford Cancer Center, 875 Blake Wilbur Drive, Palo Alto, California, 2nd Floor Conference Room CC2105. Contact Group Leader, Lenn Fechter, RN, BSN at: 650-725-0744.
- **Folsom, California MDS Support Group**: For more information call Jalil Fardanesh at 916-984-6468, email jfardanesh@gmail.com.

International

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

Patients and Caregivers LIVING with MDS Forum
SAN FRANCISCO, CALIFORNIA – MARCH 2014

Guest Speakers:
Peter L. Greenberg, MD and Lenn Fechter, RN, BSN

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.

IN YOUR WORDS

TESTIMONIALS

I'm an MDS patient and a member of the MDS Foundation.

"Thank you for the BBoH – my copy is rapidly becoming worn by my almost constant research through it."
Judy DeWeese

"Thank you for very useful information!!!"
Denise Sharp

"I can never thank you enough for referring me to Dr. Richard Stone and getting me in so soon. I just have to thank you. It feels like a cloud has been lifted off of my shoulders. "
Bottom line. Yes, I have MDS but there are 4 ways to treat mine but we are taking the plan I have now. Thanks again. Keep up helping people.
Beverly Bobroske

"Thanks for all you do for MDS."
Barbara Truemper-Green

"Thank you for providing the website and supportive materials such as the handbook."
Margaret Schardong

"Just wanted to thank you for such a nice symposium last Saturday in Indianapolis."
We have attended at least two and they have all been wonderful. Thank you for all your hard work.
Linda Berger

"Thank you for the BBoH – it is a valuable resource."
Dave Agrey

"Thank you very much for all of your mailings – you'll never know how much we appreciate your support."
Deanna and Grady Courtney

"The MDS Foundation is fantastic, a group truly committed to MDS patient well-being."
Scott Megaffin

"I wanted to let you know that I loved attending the patient forum. It was superb and very well done."
I introduced myself and spoke to many of the patients, and their loving caregivers. I listened to their stories, which despite their circumstances, were filled with hope and gratitude for their lives and loved ones. I readily recognized their struggles and questions based upon my experience with my mother. The session was helpful and very informative—the oncology nurse did an excellent job of dismissing worries and concerns with facts and information. Thank you for the invitation — I received a lot from attending."
Deborah J. Peirce

"Thank you for your work!"
Kevin Chestnut

"Thanks for your great information."
Deb Smulyan

See BBoH on page 10.

Building Blocks of Hope

HEALTHY BODY HEALTHY MIND

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

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

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

To view this episode online go to http://www.itvisus.com/programs/hbhm/episode_ 2601.asp or to order your free DVD copy today email dmurray@mds-foundation.org or call 800-MDS-0839.

Kick It In...

Janna Pelle
Brooklyn, New York

I have known for a long time that I want to change lives with my music. But only recently did I realize I could save lives with my music.

When my Dad was diagnosed with high-risk MDS in October 2013, I did not fully understand what this meant. It was presented to me as "pre-Leukemia," "curable," and "unfortunate, but Dad's going to be OK." But as I started to discover on my own, just because MDS wasn't as well-known as leukemia or other types of cancer didn't mean it wasn't as serious. As I learned more about MDS, I began to understand the severity of the situation, and wanted nothing more than to be with my Dad every moment of every day.

Living in New York City away from my parents' home in Miami, I began to feel exceedingly helpless and disconnected. I have been living as a musician in Brooklyn for about a year now, and founded a personalized songwriting company called Present Productions, in addition to actively pursuing my own music career. But during this difficult time, all I could think about was my Dad lying in a hospital bed for a month–the active, vibrant, runner/cyclist/scuba-diver; the passionate man with a great sense of humor (not to mention a full head of hair and a big beard).

His physical appearance didn't shock me, however; what shocked me was how obviously drained he was – his face for the first time since I had ever known him, lacking expression.

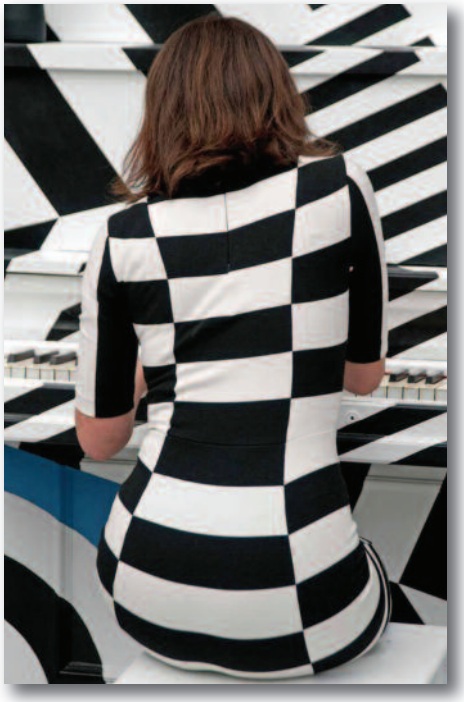
I very seriously considered moving back home to Miami, but my Dad did not want me to put my life and dreams in New York on hold. He jokingly said, "Maybe you can write a song about a bone-marrow transplant. You say you're personalized songwriting for any occasion." Though he wasn't entirely serious when he made the request, I took it seriously, and decided that it would be my next project.

The songwriting process was easy – because my Dad was a marathon runner, he always gave me and my younger brother advice about life in the form of an extended metaphor that had to do with running – so I decided to do the same.

One of the phrases that we often cheered from the sidelines in my Dad's marathon-running days was, "Kick it in!" – a phrase that is intended to give runners that extra push of motivation before reaching the finish line – and exactly what my Dad needed.

One of the phrases that we often cheered from the sidelines in my Dad's marathon-running days was, "Kick it in!" – a phrase that is intended to give runners that extra push of motivation before reaching the finish line – and exactly what my Dad needed. I wrote the song based on this phrase of encouragement, and professionally recorded it through Present Productions. The song also included the extended metaphor that my Dad's diagnosis was just "another race you have to run," another scuba dive, another cycling accident, another mountain to ski – it was just another journey that would undoubtedly have its challenges, but where he would always reach the finish line.

When I visited my Dad on the day of his bone marrow transplant, I played him the song. The expression on his face while listening to it was the most fulfilling and gratifying thing I have ever experienced. (In other words... he cried! Mission accomplished!) My dad then sent the song to all of his friends in an email, giving Present Productions the best testimonial we will probably ever receive: "If she can write a song about a bone-marrow transplant, she can write a song about anything."



But even after writing "Kick It In," I soon realized that I couldn't stop writing songs inspired by my Dad, and that it was affecting my original music as well. I soon had enough songs to release an album, and decided to dedicate it not only to my Dad, but to MDS research at large.

The album, entitled "The Show Must Go On," contains a variety of songs intended to motivate and encourage my Dad through this long and arduous journey to recovery. While I had written most of the songs since my Dad's diagnosis, I also decided to include my hit single, "Machine," which I wrote long before learning what MDS even was. The song was initially about working towards my goal of pursuing a successful music career, but could be applied to anyone who has a goal they are working nonstop to attain. Since my Dad's diagnosis, however, the song has taken on a new meaning every time I perform it. The chorus, "I'm working like a machine for you baby, so no no no please don't you break me," now makes me think of my Dad's relationship with his own body, and his journey towards a full recovery. He's still working towards a goal nonstop every day, but surely not the original goal I meant when I wrote the song.

That's the beauty, I think, of all of the songs on this album—even though they're personal to me and my family, I believe they are relatable—and this is why I would love to share them with you. I will also be hosting a benefit concert in New York in the near future to promote the album, raise awareness about MDS, and encourage people to sign up to be bone marrow donors. The album will be "pay what you wish" with all of the proceeds going to The MDS Foundation and MDS research.

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I never thought of myself as a music therapist. But it was certainly therapeutic for me to write these songs. It is my hope that they will now be therapeutic to those who listen to them, and to those who receive a donor because of their efforts.

But above all, I hope that my music is therapy to those living with MDS, and encourages them to "Kick It In."

Janna Pelle is a dynamic pianist/performer/singer/songwriter living in Brooklyn, New York. More information about her personalized song-writing company, Present Productions, can be found at www.presentproductionsmusic.com. You can listen to her original music on iTunes, Spotify, or her website, www.jannapelle.com.

Thank you Janna for creating this inspirational album dedicated to your father, Tony Pelle, who was recently diagnosed with high-risk MDS. All songs on this album are inspired by her father's diagnosis, and how it has affected her and her family. The album is "Pay What You Wish," with all proceeds of album sales going to the MDS Foundation and MDS research.

Make a donation and get your album today at https://jannapelle.bandcamp.com/album/the-show-must-go-on.

My Story

Lynn Hale
Burgess Hill, United Kingdom

My story is perhaps a little bit unusual from most MDS stories in the fact that I was diagnosed 33 years ago when I was just 17 years old! Ironically I had been to the hospital for an interview for a secretarial position after finishing College with the necessary qualifications. The Manager interviewing me was showing me around the department when I started feeling faint and unable to stop myself fainted in his arms! Needless to say I did not get the job but in a way something far more important came out of that interview. I went along to my GP and explained what had happened and he ran some blood checks to make sure I wasn't anaemic or another deficiency. It was very strange but my mum got a call from the GP just a few hours later saying I needed to be in hospital that there was something indicating that I may have something more sinister like Leukemia. It's strange but at that age I remember not even being that bothered perhaps it was because I didn't understand the severity of such a diagnosis would be but my mum looked terrified. After a very painful bone marrow biopsy in the hospital, I eventually got the diagnosis that I had Sideroblastic Anaemia or RARS. Back in those days there was not one mention of myelodysplastic syndromes and I felt like I was looking down on someone else's life as I didn't feel ill, look ill or act ill! I was a young girl wanting to get on with my life and this was a real inconvenience!

My story is perhaps a little bit unusual from most MDS stories in the fact that I was diagnosed 33 years ago when I was just 17 years old!

Even though I used to have a lower HB blood count I could live with that and didn't need blood transfusions at that point, I was given Vitamin B6 and Folic Acid which didn't appear to make things better or worse. It wasn't until I was 23 and I was feeling a bit weary with Xmas shopping that it was discovered I was walking around with a HB of just 5! One blood transfusion later I was feeling wonderful and back to my normal life of working and a newly married life. It was always my intention to have children and even though my consultant at the time advised me not to I was determined to not let my illness define me and stop me from doing things. I gave birth to 3 wonderful children although not such straightforward pregnancies with blood transfusions keeping us all healthy and alive. Over the years my illness showed itself sporadically in different ways – I used to go down with infections and viruses very easily and have occasional blood transfusions. Back then no wonder drugs existed like there are now, I just got on with raising my children and thinking the tiredness was what all mums get. I guess my MDS simmered away for quite a long time without doing anything drastic and I wasn't that concerned as I had never been told how potentially serious it could turn out to be so I was blissfully ignorant. All the consultants told me how rare it was for someone my age to have this and I could have possibly been born with this. Looking back when I was very young I was quite poorly and in photos I did look very pale but all the genetic tests have proved inconclusive to this theory. Five years ago was really the point that my illness changed dramatically and I went from having an occasional blood transfusion maybe once or twice a year to being completely blood transfusion dependant having 3 units of packed cells every 3–4 weeks. Whereas the illness has not impacted on my life in a major way it then became more serious business as I was working full time and having severe fatigue and aches and pains. I had never heard of 'iron overload' before or even thought that blood transfusions can give you all this extra iron that your body especially your liver, heart and joints do not need! So on top of the MDS, I developed secondary Haemochromatosis and needed chelation drugs to eliminate the iron from

my body. After being referred to Kings Hospital and Professor Mufti, I started to understand more about the illness that there was low risk and high risk and what I had was called RARS non del 5q type of MDS which is low risk. He also explained that there would be a possibility that I would need a bone marrow transplant as I had been having so many blood transfusions and starting to feel more unwell. He did a bone marrow donor search and I was so very lucky to have a 10/10 match. Prof. Mufti and I agreed to hold back on the transplant for a while as I still had lots of things planned, and in fact the illness and news made me want to take life by the horns and go for it! My husband and I booked lots of breaks away which did me a world of good and rejuvenated me and I started to make the most of my time at home (I gave up work) by cooking and taking up gardening. I never saw it as a possible end of my life but just the beginning. There are so many new treatments available now which there wasn't when I was younger. I have seen huge advances in the treatment of MDS and know patients that are doing really well on them. I am hoping to go on Revlimid or a drug trial this year so things are looking very hopeful. My MDS is part of my life and part of me and I don't ever wish, Why me? It's made me stronger, with more empathy and I appreciate everything and everyone so much more. Physically I do feel much worse with tiredness, sickness and bone pain but on a positive note, I have had many years when I felt perfectly ok despite having the illness. Being positive, happy and having a good balance in my life hasn't let the illness define me. If I was to advise any new MDS patient of what could really help them it would be having the support and friendship of other MDS patients as it has been AMAZING!! Out of something so negative in your life, you can find something so positive. You can build true friendships which gives you a sense of not being alone in this world of MDS while learning from each other.

Hope for MDS...

Rachel Rosenfeld
Commack, New York

My grandfather, Martin Wexler, passed away in November due to myelodysplastic syndromes (MDS). He had this illness for about ten years. He would go to his hematologist regularly and was given the proper medications to help manage this chronic disease. Unfortunately, my grandmother developed dementia, and he became her caregiver. She passed away eighteen months before he did. Being a caregiver is a very difficult job to begin with and all the while he was suffering from this chronic illness. He ended up developing pneumonia and was hospitalized for four months. My mother and aunt spent every day at the hospital to make sure he was being taken care of properly. This was an extremely difficult time for them because they just lost their mother and now their father was fighting for his life. His blood levels eventually got worse and despite all that was tried he passed on.

I will always love, remember and cherish his kindness and remember the interest he shared about every aspect about my life as well as his whole family. The close relationship I shared with him is something I will value and hold close to my heart forever. He was a Korean War Veteran and when we had a military funeral I felt so proud of him knowing he served our country the way that he did. I will always miss both my grandmother and grandfather and will remember the wonderful people that they were. There is not a day that goes by that they are not in my thoughts. Although our time together was cut short, he left my family with the most wonderful memories, and for that I feel grateful.

My grandfather took a particular interest in my hobby of jewelry making and everyday he would ask to see new design ideas. I would love coming home to newspaper and magazine clippings on the kitchen table of ideas he found throughout

the day. Being a businessman himself, he taught me how to turn my passion into a business. This is what inspired me and my sister to begin making MDS awareness bracelets in memory of our grandfather and all others suffering. Fifty percent of the proceeds from each handmade "Hope for MDS" engraved bracelet will be donated to the MDS Foundation to help raise money for more research and hopefully a cure so that one day all those affected will be able to overcome this illness.

THANK YOU Rachel Rosenfeld for creating this Hope for MDS unisex bracelet in memory of your grandfather Martin Wexler! 50% of all proceeds will be donated to the MDS Foundation. Order yours today at https://www.etsy.com/listing/172901804/mds-myelodysplastic-sydrome-awareness?ref=cat_gallery_15.

In His Memory...

This March 20, 2014 my father would have been 85 years old…he passed away November 3, 2013 from MDS. He was the love of my life…he had been diagnosed with MDS in the fall of 2012 when I was training and prepping to participate in the 23rd edition of the Rallye Aicha des Gazelles in Morocco scheduled for March 2013.

In the beginning it was just his hemoglobin that was affected and the treatment with Aranesp worked well for almost 6 months then his WBCs and platelets started to be affected and he was transitioned to Vidaza with an occasional transfusion.

I remember his last birthday, just like it was yesterday—it was March 20th, 2013, the day the rallye started. I was in Morocco getting ready to participate in the largest all-female off road rally raid in the world. I called him from Morocco to wish him a "happy birthday" and the tears just flowed. It was my last phone call before the rallye as we have to turn in all electronic devices to the rallye officials before we hit the desert. It was nice to hear his voice—definitely a needed reassurance before I would embark on the most challenging event in my life. It was then that I knew that it was time for me to be there for my Dad just as he had been there for me all my life. My Dad, affectionately called "Jaulk" by all who knew him, was my rock. He was always able to keep me on an even keel, weather the storms, advise me on major decisions and guide me along the way. He taught me to live life to the fullest as he did. With his love for WII warbirds, he flew a T6 trainer in Florida at the age of 75, his love for woodworking, cars, cruises and all things jazz, just to name a few.

When I got back to the USA after completing the rallye, I reduced my work schedule so I could help my mother take care of Dad. I took him for many of his visits to the Fox Chase Cancer Center where he received his courses of Vidaza and occasional blood transfusions. We would sit and work on the crossword puzzles he did every day, chat with the nurses and other patients. These were very special times I spent with my Dad. It felt good to be there for him, something he had always done for me and he would tell me all the time how much he appreciated me being there for him. He was a great man—very unassuming, with integrity and honesty, his philosophies were simple.

I will go back to Morocco in 2015 to participate in the 25th anniversary of the Rallye Aicha des Gazelles in his honor and to raise awareness of MDS. A portion of the monies raised for my registration fees will go to the MDS Foundation.

If you would like to follow our progress as we prepare for the 25th anniversary of the Rallye Aicha de Gazelles in 2015, please check out our website www.ladycruisers182.com. For more information on the rallye go to www.rallyeaichadesgazelles.com

Thank you for your support!

Pat Klishevich, Aston, PA
Pilot Lady Cruisers Equipage #182

My Dad, My Hero

Michele Schroeder
Floral Park, New York

"Dad, there is something going on with your bone marrow, that can possibly lead to a blood cancer". Some images never leave one's mind. I remember that day like it was yesterday…walking into the house, finding the courage and telling my dad. At the time I was a nurse for 11 years and was used to being on the other side of the fence supporting my patients and their families. You see things from a whole new perspective when it hits home. I always knew my dad was a brave and courageous man, but the way he remained strong and his eagerness to fight the battle from day one left me beyond amazed.

Two weeks earlier….Anthony's journey began with a phone call about a random blood test by his endocrinologist that showed changes in his normal hemoglobin, hematocrit, white blood cells and platelets. As my dad walked Otis, our pug and his best friend, he told me what was going on. Many thoughts ran through my head, how could they not, being a nurse working in a Medicine/Oncology/Hematology unit. So as repeat blood tests were being run which confirmed the previous counts, I made an appointment for my dad to see a Hematologist where I worked. The first appointment he could get from the doctor recommended by his primary was at least two weeks. As a daughter but more so as a nurse I was not going to let my dad or family wait, anticipating what this could be and as we all know time is essential.

I was a nurse and used to being on the other side of the fence supporting my patients and their families. You see things from a whole new perspective when it hits home.

In March 2011, my dad, at the age of 68, was officially diagnosed through a bone marrow biopsy with High Grade MDS. A whirlwind of emotions for my dad along with my mom, brother, sister-in-law and me erupted: we cried, shared how we were scared and feeling, supported each other but most of all we lived day by day and figured things out as they came about. Initially my dad was started on Revlimid because he had the 5q- gene mutation in his blood marrow. We are not really sure what caused his diagnosis of myelodysplastic syndromes, but honestly in the grand scheme of things it wasn't a focus. The priority was WHAT ARE WE GOING TO DO NOW? The thought was that the gene mutation that my dad had was receptive to this medication.

If you knew Anthony, you knew that he had an absolute hunger for knowledge, education and life. In his early 60's he set out to complete his bachelor's degree in college and when that was done he wanted more continuing on for his Master's. As a daughter I was so proud, here I was a year or two out of college and couldn't be happier to be done with school and all I wondered was why does my dad want to go to school? My dad's love for education gave him drive; his passion was for helping special needs young adults. Even after he retired from the New York City public school system, his second career, he still went back temporarily to teach classes on weekends on building robots, he never could get too far away from his passion. MDS became his next area of learning as he wanted to be smarter than the disease. He embraced his diagnosis. I remember him saying this is not cancer yet and with that giving us one of his warm smiles.

The Obstacles Ahead

Blood counts continued to drop, continuing to change my dad's lifestyle, but not stopping him from things he wanted to do. He eventually had to come off of the Coumadin for his atrial fibrillation because of the risk of bleeding. His white blood counts continued to drop raising awareness to the risk of infection and changes towards his dietary lifestyle. Anthony loved to cook and was really good at it. My dad spoiled my mom, brother, me, family and friends with his delicious dishes. Anytime my co-workers and I had a monthly birthday party it was dad's chicken parmesan that was talked about and asked for. I didn't have a choice in what I was bringing. Even when my dad was trying to save his energy in his last couple of weeks, he was still giving me recipes and teaching me little tricks. I will never forget the last recipe he wrote for me and that I cooked for him, beef short ribs.

As things progressed 3–4 months into diagnosis he discontinued Revlimid and began Vidaza with blood transfusions as needed. My mom and I rotated going to my dad's treatments with him pending on our work schedules. I valued these hours that I spent with my dad, as my mom did too. We watched the cooking shows together—*The Chew* and *Rachel Ray*—and we would watch a little *Bonanza* (one of my dad's favorites) and always a little *Who Wants Be a Millionaire*. And lastly, we always looked forward to what was for lunch. One of my favorite memories was in November of 2011 when we were preparing for the birth of my nephew, Anthony's first grandchild. I chose to do all the centerpieces for the shower, more than I could handle, but my

dad pitched in and while getting his blood we spent the time rolling diapers together for the diaper cake centerpieces. Peter, his grandchild, was born two weeks after his passing. My dad had a way of knowing things and I think the oncoming birth of Peter gave him comfort during his last days as he knew his family would be soon welcoming a new addition. Peter is that light for them as he is for me too.

The chemotherapy added to my dad's neutropenia and towards the fall of 2011 my dad had to be admitted to the hospital. With the first hospitalization, my dad had a repeat bone marrow biopsy that showed significant changes in his bone marrow from the Vidaza. When fighting a battle, any good news helps, so with the news of what was happening in my dad's bone marrow he would attempt to push through these set-backs. The complications from the chemotherapy are what significantly took a toll on my dad's body. He was in the hospital two additional times after the first. The first couple of months were a very stressful time for the family, we rotated shifts between my mom, brother and I being with my dad. Into my life, towards the beginning of my dad's diagnosis came the man that is now today my husband. My dad and Joe's relationship grew rather quickly, what they had in common — their love for the GIANTS and of course ME. Much of the time getting to know each other were the nights spent in the hospital. I believe my dad knew in his heart that I found Mr. Right and he made my mother promise to give me the wedding of my dreams.

My dad loved the holidays, and thankfully he was home from his second hospitalization right before Thanksgiving 2011 and even though it wasn't a typical holiday he was able to be with his family. He was able to be part of the Baby shower for Peter in December and see his family and he did it with a smile. He gave Peter a very special present (my mom's idea of course), he recorded the story of the Three

Little Pigs for Peter to have, which is such a special keepsake for all of us. And he was home for his favorite, Christmas 2011. I remember the two times he came back home from the hospital how happy he was, the smile on his face as he walked through that door, especially when he saw his dogs, Otis and Domino. "Getting home" was not an easy thing as many of us in this world have experienced. Dad needed to be on extended antibiotic therapy which was costly, and insurance companies never make that easy, but as a family we made it happen. Adjustments had to be made to the house to ensure my dad's safety but my mom did whatever it took.

On a sunny, winter morning of January 2012 my dad made a point to walk out the front door of the house instead of going out the back door like he normally would for a doctor's appointment. Unfortunately he was never able to walk back in. The third time around we did what we always did as a family we supported each other and the power of family presence. The NFL Playoffs were on with the Giants headed for the Superbowl. Anthony was very passionate about football. My dad, Chris and I spent Saturday evenings and Sunday afternoons in the hospital watching the games. It wasn't the way I grew up in the Massone household though. On a typical football Sunday, I would want to run out the door listening to the two football fanatics screaming at the TV while the Jets and Giants competed but over the years football has grown on me.

The last days of my dad's journey with MDS was spent in the ICU and he was very aware of what was going on around him. We each had our time with him, reminiscing, talking and just holding hands. I even talked with my dad about my career, and how the last 11 months had me questioning if I wanted to continue being a nurse. I even tossed around the thought of becoming a chef. Realizing what was going on was breaking me and I really doubted if I would find the strength and courage to be a nurse anymore. He told me just to go with my gut and whatever I wanted to do he would support me. We all had quiet time together listening to music and Johnny Mathis will always remind me of my parents. No matter how sad he was to leave us I thank him for his honesty; he knew he was going to a wonderful place and he made sure my mom, brother and I knew that he was not scared. His faith and religion were so threaded into his life and helped him find peace. Throughout his journey even when he was not able to drive anymore, I made an agreement with my dad to take him to church. We would go to the 12 noon mass and then of course after mass we would go to one of our favorite

spots *Nick's Greek Restaurant*, I would have a Bloody Mary and with no questions asked dad would have his sangria. In honor of my dad it was very important to me that Joe and I get married in church, but not just any church, the one my dad grew up attending. In order to do this I had to complete my sacraments into the Catholic religion, which I embraced for so many reasons that my dad had taught me. To make it even more special we were married by my dad's uncle, Father Mike. On October 5, 2013, Joey and I got married at Our Lady of Mount Carmel.

The Days to Follow

So much of what I am today and what makes things get easier are the experiences and memories of my father. I am who I am because of my dad and mom. His battle with MDS ended on January 21, 2012, it was short, 11 months to be exact. I choose not to focus on the negative but on the positive and I hope many messages come out of my tribute in memory of my father. The biggest message that I want to convey and that I know my dad would agree is that no disease should change who you are and remember to LIVE, LAUGH, LOVE and make those unforgettable memories. I am thankful for all the lessons learned, the stories left behind, my amazing family, friends and special nurses who took care of us during this difficult journey. I am thankful for the 34 years of wonderful memories I had with my dad. Joe and I donated to the MDS Foundation to support the research, dedication and hard work that those involved in the Foundation do on a daily basis. I am sorry that my dad could not be a part of this cause but through his memory, Joe and I will do what we can to support the MDS Foundation.

I have one last thing to share with all the readers: our angels are never too far away. Of course they are always in our hearts, but just take time to look at the things around you and the little signs; I believe my dad is always with me and my family. The signs may not make sense to all, but to some they mean everything if we take a minute to think about it. For my family it was a random Splenda packet found on the kitchen floor by mom, long after dad had passed on and finding the photo holder for my wedding bouquet to hold dad's photo which I miraculously found in a store when I had just about given up hope in finding one. And as for the Giants in 2012 they made it to Superbowl after a nail biting game against the 49ers. Anthony was always that #1 Giant's fan. On that Sunday afternoon, we watched the Giants win to make it to the Superbowl with the final goal being kicked by Lawrence Tynes – Anthony would have loved this game! During Tyne's interview after the game he stated, "I dreamed I would hit it from 42 yards, left hash." The #42 was our sign from dad that he was with us and knew the Giants were going to the Superbowl – Anthony J. Massone was born in 1942.

...Our angels are never far away. Of course they are always in our hearts, but just take time to look at the things around you and the little signs; I believe my dad is always with me and my family.

Stay Connected...

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GET INVOLVED!

Join the MDSF Development Committee!

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

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

SUPPORT THE MDSF!

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

Please think of the MDS Foundation in your charitable giving this year and help people LIVING with MDS.

THANK YOU FOR YOUR CONTINUED SUPPORT!

SIGN UP TO VOLUNTEER!

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

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.

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.*

NAME OF INSTITUTION:
Eli Lilly and Company

TRIAL NUMBER:
NCT02008318

Title of Trial or Description:
Phase 2/3 Study evaluating a study drug in Very Low-, Low-, and Intermediate-Risk Patients With Myelodysplastic Syndromes.

ELI LILLY

Currently Recruiting Participants.

The purpose of this study is to investigate the effect of the study drug on red blood cells in participants with myelodysplastic syndromes (MDS). Participants with different degrees of 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.*

NAME OF INSTITUTION:
Mirati Therapeutics

TRIAL NUMBER:
0103-014 (NCT 02018926)

Title of Trial:
A Phase I/II Multi-Center Study of Mocetinostat in Combination with Azacitidine in Subjects with Intermediate or High Risk Myelodysplastic Syndromes (MDS).

MIRATI

Description: The primary objective of this placebo-controlled (randomized) research trial is to further define the safety profile in subjects with MDS treated with the investigational drug mocetinostat in combination with 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:

UNITED STATES

ARIZONA

Mayo Clinic Hospital
Scottsdale, Arizona
Raoul Tibes, MD, PhD

The University of Arizona Cancer Center
Tucson, Arizona
Ravi Krishnadasan, MD, FACP

CALIFORNIA

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

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

Moores Cancer Center at the University of California, San Diego
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Connect® MDS|AML Disease Registry

An MDS/AML Prospective Observational Study

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
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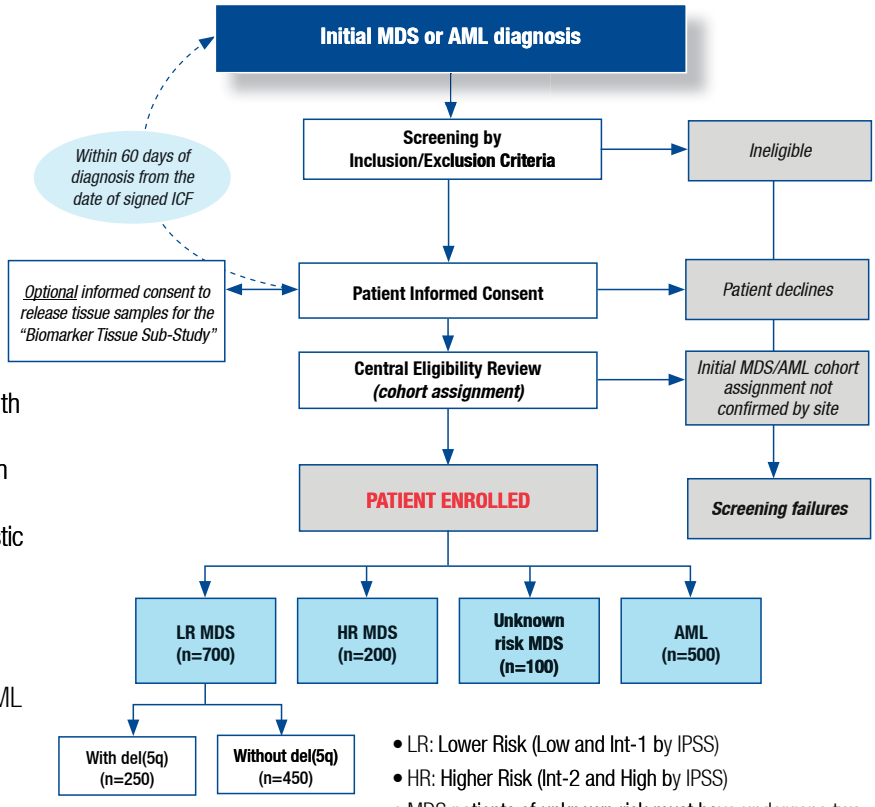

- LR: Lower Risk (Low and Int-1 by IPSS)
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- MDS patients of unknown risk must have undergone two unsuccessful bone marrow cytogenetic testing attempts
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