

MDS NEWS HIGHLIGHTS

FROM THE GUEST EDITOR'S DESK

■ Frailty as a Patient-Related Prognostic Factor in MDS

Presented by *Rena Buckstein, MD, FRCPC*

Head Hematology Site Group

Co-Director of MDS Research Program

Odette Cancer Center, Toronto, Ontario



13TH INTERNATIONAL SYMPOSIUM ON MYELOYDYSPLASTIC SYNDROMES

April 29 – May 2, 2015 • Washington, DC

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Message Board

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Frailty as a Patient-Related Prognostic Factor in MDS



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Typically, when a hematologist is faced with a patient with a new diagnosis of MDS, his/her first approach is to calculate an MDS specific 'risk-score' capable of predicting survival and AML propensity. This helps guide therapeutic recommendations and decision making for both the physician and the patient. While there are a plethora of risk scores available,¹⁻⁴ the most commonly deployed risk score (at present) is the revised IPSS (IPSS-R)² which divides newly diagnosed MDS patients into one of 5 risk categories based on the number and depth of cytopenias, cytogenetic abnormalities and the % of blasts in the bone marrow. This risk score is further discriminated by age (IPSS-RA), LDH and ECOG performance status and will be further refined by the incorporation of standardized molecular mutation testing in the near future.⁵⁻⁷

The Impact of Comorbidities

Myelodysplastic syndromes, like many cancers, disproportionately affects those aged 70 years or older.⁸ Just as the seed (the MDS) is highly heterogeneous, so is the soil (the patient) in which the disease arises – heterogeneous with respect to physical reserves, comorbidity, disability and geriatric conditions. Comorbidities consist of one or more diseases or disorders that exist in addition to an index disease. In the

US, 45% of the general population and 88% of the population aged 65 years or older have at least one chronic condition.⁹ Comorbidities may impact survival or treatment among cancer patients¹⁰ in general and AML patients specifically.¹¹ In MDS, comorbidity risk scores retrospectively calculated using a variety of generic instruments including the Charlson comorbidity index (CCI),¹² the hematopoietic stem cell transplantation comorbidity index (HCT-CI),¹³ the adult comorbidity evaluation-27 scale (ACE-27),¹⁴ and an MDS specific CI¹⁵ have been shown to independently impact on the overall survival of MDS patients. In particular, the comorbidities cardiac, liver, renal, pulmonary disease and solid tumours independently affect the risk of death in MDS patients and shorten their survivals^{15,16} in primarily lower risk MDS patients where non-leukemic deaths predominate. While comorbidity is certainly important to consider, geriatric oncologists have shown that comorbidity and functional status are independent¹⁷ and performance status scales or comorbidity indices are insufficient tools for 'staging the aging' and separating the fit from the vulnerable and from the frail.

Definition of Frailty

Frailty is considered to be a state of decreased physiological reserves, arising from cumulative deficits in several physiological systems and resulting in a diminished resistance to stressors. MDS complications (anemia, bleeding, infections, transfusion dependence) and its treatments are substantial stressors that diminish physiological reserves so the concept of frailty is particularly relevant for older patients with MDS. In geriatric oncology, a complete geriatric assessment (CGA) is done to detect disabilities and geriatric conditions that can contribute to frailty. A CGA is a systematic procedure that objectively appraises the health status of elderly people focusing on somatic,

functional and psychological domains.¹⁸ It includes a compilation of reliable and valid tools to assess geriatric domains such as comorbidity, functional status, physical performance, cognitive status, psychological status, nutritional status, medication review and social support. Geriatric assessment is, in fact, recommended by the National Comprehensive Cancer network guidelines for senior adult oncology¹⁹ and has been recently championed in the treatment of elderly AML²⁰ and MDS patients.²¹ In AML patients considered for intensive therapy, the most promising predictors are measures of physical function, cognition and symptoms.^{22,23} In a prospective AML study, objectively measured physical performance and cognitive function were more important than chronologic age in predicting survival and measuring these 2 clinical characteristics increased the power of a predictive AML clinical model by 60%.²² In another prospective study of elderly AML (n=132)/MDS (n=63), any impairment in activities of daily living, a Karnofsky performance status of <80% and a quality of life/fatigue score of greater than 50 were determined to be independently prognostic for impaired overall survival in non-intensively treated patients.²³

Tools to Evaluate Frailty

Because a CGA is time-consuming, research is focusing on screening methods to identify fit elderly patients who are able to receive standard cancer treatment based on the complete treatment schedule and vulnerable patients who should subsequently receive a CGA to guide tailoring of their treatment regimen.²⁴ There are a variety of frailty screening methods (vulnerable elders survey-13 (VES-13),²⁵ geriatric 8 (G8),²⁶ Groningen frailty index (GFI)²⁷ and Fried frailty criteria²⁸ to name a few with variable sensitivities (51-88%) and specificities (43-100%) to detect true frailty (as defined by the gold standard CGA) in elderly patients with cancer.²⁴

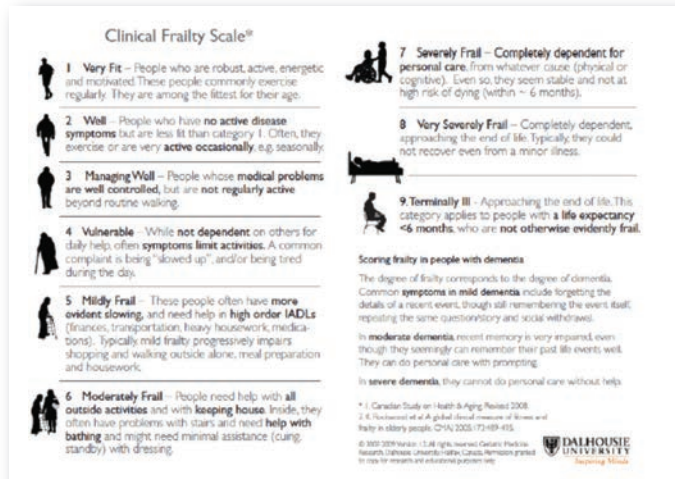


Figure 1. Rockwood Clinical Frailty Scale

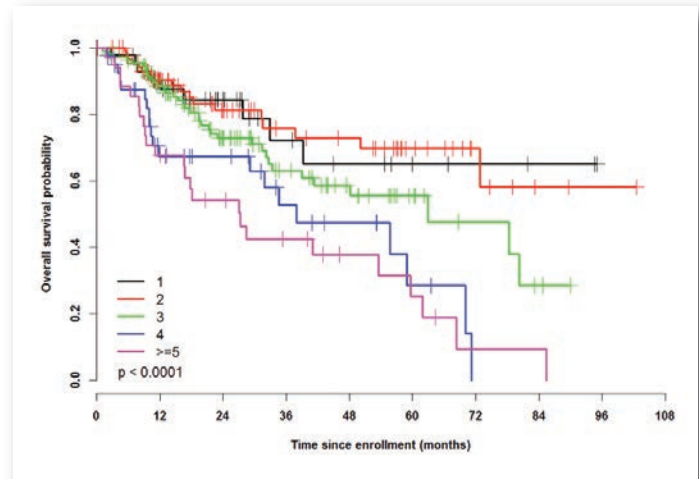


Figure 2. Overall survival according to clinical frailty scores.

Rockwood and colleagues developed a simple 7-point clinical frailty scale (CFS), modified in 2008 to 9 points, **Figure 1**) based on clinical judgment and physical examination that was highly correlated with the more conventionally defined Frailty Index (a count of 70 deficits). The scale is based largely on a person's level of physical activity, symptoms and function for basic and instrumental activities of daily living (ADL and IADL). Each 1-category increment of the scale significantly increased the medium-term risks of death (21.2%) and entry into an institution (23.9%) among older adults, independent of age, sex and education. More importantly, this CFS performed better than measures of cognition, function or CM in assessing the risk for death.²⁹

The Impact of Frailty and Comorbidity in a Canadian MDS Registry

In a prospective Canadian national MDS registry, clinical frailty (using the Rockwood CFS), comorbidity, independent activities of daily living, quality of life and 3 selected physical performance tests were assessed at baseline enrollment and on a yearly basis in 330 patients. We found that 13% of MDS patients were vulnerable (CFS 4) and 12% were frail (CFS 5+). Forty five % had at least one disability on a scale that assesses independent activities of daily living and 50% had at least 1 comorbidity. Survival from enrollment declined with

increasing CFS scores (**Figure 2**) and scores of 1–3 versus 4+ were able to further refine the survivals predicted by the IPSS-RA (**Figure 3**). The impact of these patient related variables in addition to disease related factors and prognostic scores was evaluated using univariable and multivariable analysis. By multivariable analysis, the IPSS-RA, frailty, and comorbidity (using the CCI) were the most significant factors independently predictive of overall

survival. This permitted the creation of a novel prognostic score for survival inclusive of both disease (IPSS-RA) and patient related factors (frailty and comorbidity) that will require validation. The use of patient related factors (frailty, comorbidity, disability, physical fitness, emotional well being, fatigue etc.) as a means of also predicting toxicity to azacitidine is currently being examined while the Canadian MDS registry continues enrollment.

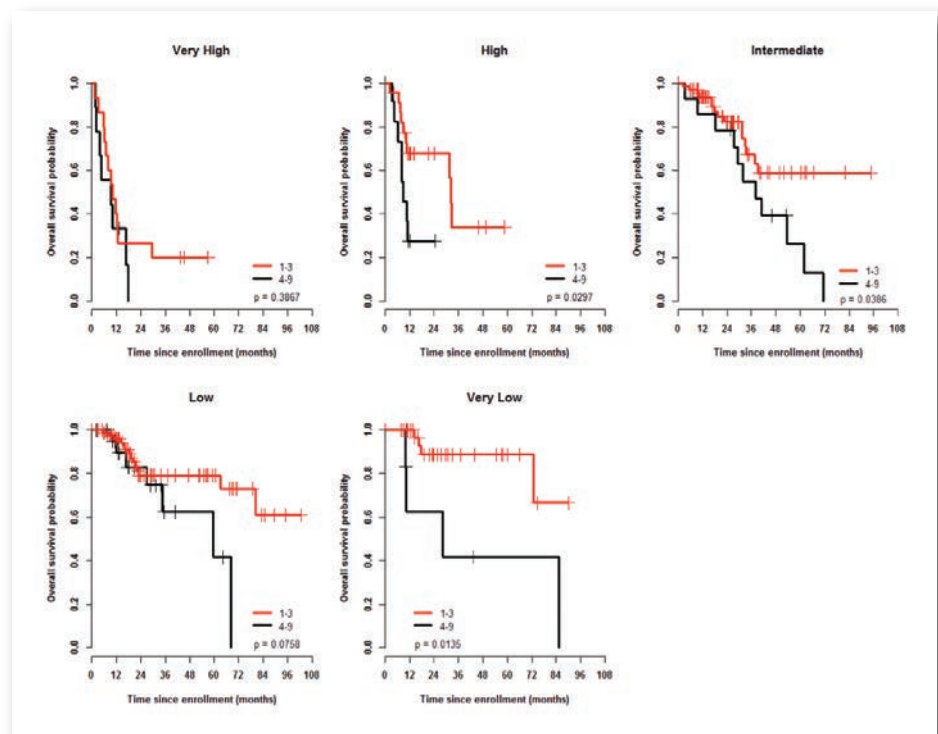


Figure 3. Overall survival according to IPSS-RA risk categories defined by frailty scores of 1–3 versus 4+.

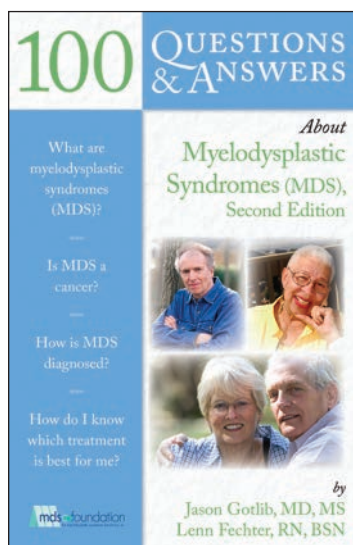
Conclusion

In MDS, the seed (MDS) within the soil (the patient) must both be considered when prognosticating survival and therapeutic tolerance. We should strive towards the creation of a comprehensive prognostic score in the future that incorporates both detailed disease related (inclusive of genetic mutations) and patient related factors such as frailty and comorbidity to better guide our therapeutic decision making and counseling of our patients. Furthermore, interventions to improve frailty (such as physical conditioning programs, transfusion and concomitant disease optimization) should be explored.

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UPDATED QUESTIONS & ANSWERS



The MDS Foundation is happy to endorse the newly revised and updated

100 QUESTIONS & ANSWERS ABOUT MYELODYSPLASTIC SYNDROMES

EMPOWER YOURSELF!

Whether you're a newly diagnosed patient, a survivor, or a loved one of someone suffering from MDS, this book offers help.

Be one of the first to receive your FREE second edition copy hot off the press by contacting the MDSF today! Now available in print and digital format.

NEW WAYS TO MANAGE MDS



HEALTHY BODY
HEALTHY MIND

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.

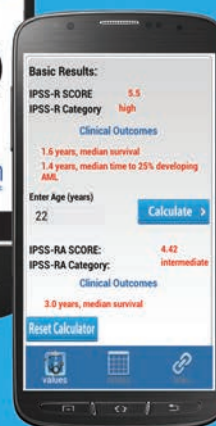
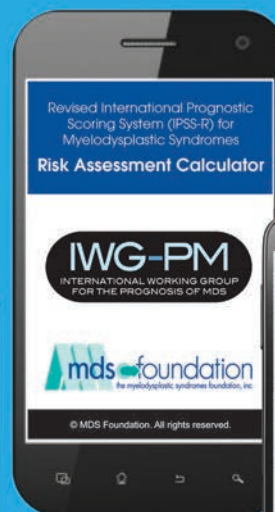
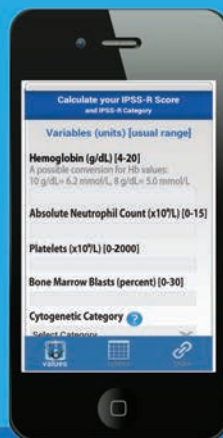
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LATEST NEWS ON THE REVISED INTERNATIONAL PROGNOSTIC SCORING SYSTEM FOR MDS

The IWG-PM Molecular Project:

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

describing analysis of combined datasets from the IWG-PM-Molecular Committee has demonstrated that TP53 mutation status divides MDS patients with complex karyotypes into distinct prognostic risk groups, with those carrying the mutation having poorer prognoses (Bejar, Papaem-

manuil, Haferlach et al, Proc ASH 2014). In addition, with ongoing studies of the group, generation of further data regarding potential molecular driver mutations for this spectrum of diseases is anticipated to provide useful targets for the future treatment of MDS patients.



The IWG-PM Working Group hard at work during their meeting held in conjunction with the 56th annual ASH Congress this past December in San Francisco.

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.

MEETING HIGHLIGHTS AND ANNOUNCEMENTS

HIGHLIGHTS FROM THE 56TH ASH ANNUAL MEETING & EXPOSITION • DECEMBER 2015

THE MDS FOUNDATION PRESENTS:

Current Therapeutic and Biologic Advances in MDS

DECEMBER 5, 2014 SAN FRANCISCO, CALIFORNIA



BREAKFAST SYMPOSIUM

On behalf of the MDS Foundation and our Board of Directors,
THANK YOU for joining us for our recent Breakfast Satellite Symposium!

Another great MDSF Symposium #ASH14!

And THANK YOU to our prestigious faculty, internationally recognized experts in the field of MDS, for their presentations.

ASH SATELLITE SYMPOSIUM



A photo of our illustrious faculty who presented the current therapeutic and biologic advances in MDS at #ASH14. Presentations are now available on our MDS Foundation website www.mds-foundation.org. L to R: Drs. Mario Cazzola, Joachim Deeg, Peter Greenberg, Stephen Nimer, Peter Valent, and Alan List



PRESENTATIONS AVAILABLE

MDS Foundation Website:
<http://www.mds-foundation.org/ash-breakfast-2014/>

THE 13TH INTERNATIONAL SYMPOSIUM ON MYELOYDYSPLASTIC SYNDROMES

MDS 2015 will attract an international audience of researchers, clinicians, scientists and educators from around the world who deal with MDS.

The MDS 2015 Symposium includes presentations delivered by renowned professionals on the latest developments in hematology.

Advancing Research & Patient Care

THE 13TH INTERNATIONAL SYMPOSIUM ON MYELOYDYSPLASTIC SYNDROMES

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



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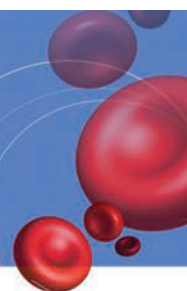
13TH INTERNATIONAL SYMPOSIUM ON MYELOYDYSPLASTIC SYNDROMES



Advancing Research & Patient Care

THE 13TH INTERNATIONAL SYMPOSIUM ON MYELOYDYSPLASTIC SYNDROMES

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



Wednesday, April 29, 2015

	Hall A	Hall B
14:00 - 17:00		Morphology Workshop – Hall B <i>Moderators: John Bennett, USA & Jean Goasguen, France</i>
17:00 - 17:45	Opening Ceremony & NEXT GEN MDS Plenary 1 <i>Chair: Steven Gore, USA</i> Making the Quantum Jump in Clinical MDS Treatment <i>Benjamin L. Ebert, USA</i>	
17:45 - 18:45	Best of Clinical Trials: Abstracts	
18:45 - 20:15	Welcome Reception & Meet the Faculty	

Thursday, April 30, 2015

	Hall A	Hall B	Hall C	Exhibition Area
08:30 - 09:00	Plenary 2: Genomics and Epigenomics <i>Chair: Timothy Graubert, USA</i> <i>Speaker: Maria A. Figueroa, USA</i>			
09:00 - 09:30	GENOMICS AND EPIGENOMICS: Abstracts	Symposium 1: Molecular Diagnostics <i>Rafael Bejar, USA</i>		
09:30 - 10:00				
10:00 - 10:30	Coffee Break, Exhibition, & Poster Viewing			
10:30 - 11:00	Plenary 3: Splicing Factors <i>Chair: Andrea Pellagatti, UK</i> <i>Speaker: Matthew J. Walter, USA</i>			
11:00 - 11:30	EPIGENETICS AND SPLICING FACTORS: Abstracts	Symposium 2: Prognostication <i>Felicita Thol, Germany</i>		
11:30 - 12:00		Symposium 3: Supportive Care including Chelation <i>Thomas Prebet, USA</i>		

13TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES

12:30 - 13:30	Lunch, Exhibition & Poster Viewing			
13:30 - 14:00	Plenary 4: MDS: Preclinical and Mouse Models <i>Chair: Peter Aplan, USA</i> <i>Speaker: Aly Karsan, Canada</i>		Nursing Education Program: Session 1 <i>Sandy Kurtin, USA</i> <i>Corien Eeltink, Netherlands</i> <i>Sara M. Tinsley, USA</i>	Poster Walk 1
14:00 -14:30	MDS PRECLINICAL AND MOUSE MODELS: Abstracts	Point/ Counterpoint 1: Do we cure patients with alloSCT? How do we prevent relapse? <i>Corey S. Cutler, USA</i> <i>Michael Luebbert, Germany</i> <i>Uwe Platzbecker, Germany</i> <i>David Steensma, USA</i>		
14:30 - 15:00				
15:00- 15:30	Coffee Break, Exhibition, & Poster Viewing			
15:30 - 16:00	Plenary 5: MDS Microenvironment <i>Chair: Amit Verma, USA</i> <i>Speaker: Andreas Trumpp, Germany</i>		Nursing Education Program: Session 2 <i>Erin Demakos, USA</i> <i>Cindy Murray, Canada</i>	
16:00 - 16:30	MDS MICROENVIRONMENT: Abstracts	Expert Panel 1 – Discussion of Submitted Cases: Difficult Diagnoses <i>Virginia M. Klimek, USA</i> <i>Olatoyosi Odenike, USA</i> <i>Bart L. Scott, USA</i> <i>Moshe Mittelman, Israel</i>		
17:00				

Friday, May 1, 2015

	Hall A	Hall B	Exhibition Area
08:30 -09:00	Plenary 6: Innate Immunity and Bone Marrow Failure States <i>Chair: Guillermo Garcia-Manero, USA</i> <i>Speaker: Daniel Starczynowski, USA</i>		
09:00 - 09:30	INNATE IMMUNITY AND BONE MARROW FAILURE STATES: Abstracts	Symposium 4: Overlap Syndromes including CMMoL <i>Eric Padron, USA</i>	
09:30 - 10:00			
10:00 - 10:30	Coffee Break, Exhibition, & Poster Viewing		
10:30 - 11:00	Plenary 7: MDS and the Aging Stem Cell <i>Chair: Chris Park, USA</i> <i>Speaker: Margaret A. Goodell, USA</i>		
11:00 - 11:30	MDS AND THE AGING STEM CELL: Abstracts	Symposium 5: Management of Lower Risk MDS <i>Aristoteles Giagounidis, Germany</i>	
11:30 - 12:00		Symposium 6: Management of Higher Risk MDS including Transplant <i>Hetty Caraway, USA</i>	
12:00-12:30		Special Lecture Dedicated to the Memory of Bob Weinberg <i>Chair: Stephen Nimer, USA</i> <i>Speaker: Sally Ann Roberts, USA</i>	

13TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES

12:30 - 13:30	Lunch, Exhibition & Poster Viewing		
13:30 - 14:00	Plenary 8: Epidemiology and Outcomes in MDS <i>Chair: Greg Abel, USA</i> <i>Speaker: Xiaomei Ma, USA</i>		
14:00 - 14:30	EPIDEMIOLOGY AND OUTCOMES IN MDS: Abstracts	Roundtable Discussion: The one international clinical trial which would most advance the treatment of MDS patients <i>Elihu H. Estey, USA,</i> <i>Valeria Santini, Italy,</i> <i>Guillermo F. Sanz, Spain,</i> <i>Mikhael Sekeres, USA,</i> <i>Norbert Vey, France</i>	Poster Walk 2
14:30 - 15:00			
15:00 - 15:30	Coffee Break, Exhibition, & Poster Viewing		
15:30 - 16:00	Plenary 9: MDS Predisposition <i>Chair: Benjamin L. Ebert, USA</i> <i>Speaker: Lucy Godley, USA</i>		
16:00 - 16:30	MDS PREDISPOSITION: Abstracts	Expert Panel 2 – Discussion of Submitted Cases: Therapeutic Decisions <i>Raphael Itzykson, France</i> <i>Rami S. Komrokji, USA</i> <i>John M. Pagel, USA</i> <i>Gail J. Roboz, USA</i>	
17:00			
19:30	Networking Dinner - National Building Museum		

Saturday, May 2, 2015

	Hall A	Hall B
08:30 - 09:00	Plenary 10: Biology of MDS Disease Progression <i>Chair: Jarek Maciejewski, USA</i> <i>Speaker: Elli Papaemmanuil, UK</i>	
09:00 - 09:30	BIOLOGY OF MDS DISEASE PROGRESSION: Abstracts	
09:30 - 10:00		
10:00 - 10:30	Coffee Break	
10:30 - 11:30	Best of Clinical Trials II: Abstracts	Patient Forum
11:30 - 12:00	BEST OF ABSTRACTS	
12:00-12:30		
12:30 - 13:00	Closing Ceremony	

Legend:

	Workshops		CLINICAL STATE OF THE ART: Expert Panel/ Roundtable Discussion/ Point-Counterpoint/Symposium
	NEXT GEN MDS: Poster Session		NEXT GEN MDS: Abstracts
	NEXT GEN MDS: Plenary Sessions		Other
	Patient Forum		Nursing Education Program

PLAN TO ATTEND...

6TH INTERNATIONAL EURASIAN HEMATOLOGY CONGRESS

The MDS Foundation is proud to once again exhibit for the third year in a row at the 6th Eurasian Hematology Congress to be held between 14-18 October 2015 at the Mardan Palace Hotel in Antalya, Turkey. Approximately 1300 colleagues from 34 countries and numerous local participants took part in their 2014 Congress. For this year, they are expecting to host a high number of participants from different countries in addition to local participants.



The Symposium includes presentations delivered by renowned professionals on the latest developments in hematology, and we are proud that Dr. Peter Greenberg from our MDS Foundation Board of Directors will again be a part of the speaking faculty. Further details, including information on the scientific program, can be found on their Congress link:

<http://www.avrasyahematoloji2015.org>

Be sure to visit our booth in the Exhibit Hall and pick up FREE copies of all of our MDS educational materials for your patients. We look forward to seeing you in Turkey!

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Practical Tools for Clinical Management of MDS



MDS - A bone marrow failure disorder

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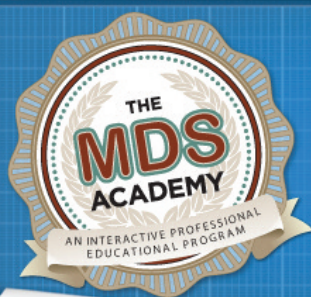
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MDS Centers of Excellence



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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.

REFERENCES IN MDS

Highlights of Latest Literature in MDS

Suneel D. Mundle, PhD
Rhea Mundle

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

DIAGNOSIS & PROGNOSIS:

- Johnson RC et al. Mesenchymal stromal cell density is increased in higher grade myelodysplastic syndromes and independently predicts survival. *Am J Clin Pathol*. 2014;142 (6):795-802. (<http://www.ncbi.nlm.nih.gov/pubmed/25389333>) Automated image analysis of tissue microarray was performed to determine CD271+ mesenchymal stromal cell (MSC) density in 125 cytopenic patients. The results demonstrated significantly increased density of MSC in higher grade MDS (n=24) as compared to lower grade MDS (n=40, p=0.02) and benign cytopenias (n=61, p<0.006). Furthermore, the MSC density predicted survival independent of revised IPSS, transfusion history, status of therapy related MDS and fibrosis (HR 3.4, p<0.001).
- Della Porta MG et al. Validation of WHO classification-based prognostic scoring system (WPSS) for myelodysplastic syndromes and comparison with the revised international prognostic scoring system (IPSS-R). A study of the international working group for prognosis in myelodysplasia (IWG-PM). *Leukemia*. 2015, Feb 27. [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25721895>) An assessment of individual WPSS parameters in 5326 untreated MDS patients revealed a strong correlation between WPSS and IPSS-R. Discrepancies were noted in some low risk cases where morphologic assessment of marrow dysplasia in individual hematopoietic lineages did not reflect peripheral cytopenias and/or blast count in the marrow. Lastly, anemia severity prognostically weighted higher in WPSS vs. IPSS-R.
- Schemenau J et al. Cellularity, characteristics of hematopoietic parameters and prognosis in myelodysplastic syndromes. *Eur J Haematol*. 2015, Jan 20 [Epub ahead of Print] (<http://www.ncbi.nlm.nih.gov/pubmed/25600827>) The median survival and rates of leukemic transformation after 2 years were significantly higher for hypercellular MDS (25 months, p<0.0005; and 33%, p=0.018 respectively), as compared to hypocellular and normocellular MDS (survival-38 and 42 months respectively and leukemic transformation rate -19% for both).
- Zeiden AM et al. (on Behalf of ECOG and North American Leukemia Intergroup). Comparison of the prognostic utility of the revised international prognostic scoring system and the French prognostic scoring system in azacitidine-treated patients with myelodysplastic syndromes. *Br J Haematol*. 2014;166:352-359 (<http://www.ncbi.nlm.nih.gov/pubmed/24712482>)

A comparison of IPSS-R with FPSS in 150 MDS patients treated with azacitidine alone or in combination with entinostat showed that both systems differentiated survival in different prognostic categories. Statistically however, FPSS had no further advantage over IPSS-R.

TREATMENT:

Demethylating Agents:

- Ørskov AD et al. Hypomethylation and up-regulation of PD-1 in T cells by azacitidine in MDS/AML patients: A rationale for combined targeting of PD-1 and DNA methylation. *Oncotarget*. 2015;Mar 18[Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/25823822>) Most patients with higher-risk myelodysplastic syndrome (MDS) at some point lose response to hypomethylating agents (HMAs). In the present study, T cell expression of immunoinhibitory receptor PD-1, that is regulated by DNA methylation, was associated with a worse overall response rate and low survival. HMAs induced PD-1 expression on T cells in treated MDS patients, thus hindering immune response against MDS blasts. So, the activation of PD-1 checkpoint in HMA treatment can serve as resistance which may be overcome by a combination therapy with PD-1 pathway inhibitor.
- Ofiran Y et al. Higher infection rate after 7-compared with 5-day cycle of azacitidine in patients with higher risk myelodysplastic syndrome. *Clin Lymphoma Myeloma Leuk*. 2015; Mar 5 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/25823643>) Infectious complications may be dose-related in azacitidine (AZA) treatment. Higher-risk patients with MDS or AML treated with AZA in 18 Israeli hospitals from 2008 to 2011 participated in a survey study. The limited analysis of infection rates following the first AZA dose displayed more frequent events with a dose of 75 mg/m² for 7 days than 75 mg/m² for 5 days. Of the 46 total events, the pathogen was bacterial in 25 and viral or fungal in 2 each respectively. No pathogen was detected in 17 cases. Infections were common in patients with platelet counts <20,000 or with poor risk cytogenetics.
- Strati P et al. Phase I/II trial of the combination of midostaurin (PKC412) and 5-azacitidine for patients with acute myeloid leukemia and myelodysplastic syndrome. *Am J Hematol*. 2015; 90(4):276-281 (<http://www.ncbi.nlm.nih.gov/pubmed/25530214>) Patients with AML or high risk MDS received 75 mg/m² azacitidine on day 1-7 of 21 day cycle in combination with midostaurin at 25 mg or 50 mg bid on days 8-21 of the first cycle and continuously thereafter. Phase I and II enrolled 14 and 40 patients respectively. The overall response rate was 26% and remission duration of 20 weeks. Best response was seen in FLT-3 mutated patients previously not treated with another FLT3 inhibitor or in patients not transplanted previously.

IMiDs:

- McGraw KL et al. Lenalidomide Induces lipid raft assembly to enhance erythropoietin receptor signaling in myelodysplastic syndrome progenitors. *PLoS One*. 2014;9(12):e114249 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25469886>)

Localization of erythropoietin receptor (EpoR) within lipid raft microdomains is essential for its signaling. The present report demonstrated that the lipid raft assembly was significantly diminished in number and size in MDS erythroid progenitors as compared to normal controls. Lenalidomide rapidly induced raft assembly, recruitment of EpoR and its signaling upon EPO stimulation with JAK2/STAT5 phosphorylation in UT7 cell line and primary MDS erythroid progenitors. The raft assembly was also associated with F-actin polymerization.

Novel Agents:

- Brayer J et al. WT1 vaccination in AML and MDS: A pilot trial with synthetic analog peptides. *Am J Hematol*. 2015;Mar 19 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25802083>) The present study assessed safety, tolerability and immunogenicity of a polyvalent WT1 peptide vaccine. Previously treated high risk MDS patients and AML patients in remission were treated with a mixture of peptides from WT1 protein along with GM-CSF. Six biweekly vaccinations followed by a maximum of 12 monthly doses were administered. Vaccinations were well tolerated with no discontinuation due to toxicity. One of the two MDS patients showed sustained transfusion independence and 2 of the 14 AML patients showed >1 year relapse free survival.
- Di Stasi A et al. Review of the results of WT1 peptide vaccination strategies for myelodysplastic syndromes and acute myeloid leukemia from nine different studies. *Front Immunol*. 2015;6:36(<http://www.ncbi.nlm.nih.gov/pubmed/25699052>) A total of 51 eligible MDS/AML patients from 9 studies reported between 2004-2012 showed clinical benefit with WT1 peptide vaccination demonstrating its safety and clinical benefit including some patients who achieved and maintained remission long term over 8 years. The emergence of WT-1 specific T cells, and normalization/reduction of WT-1 mRNA levels were both associated with progression free survival.
- Garcia-Manero G et al. A phase I study of oral ARRY-614, a p38 MAPK/Tie2 dual inhibitor, in patients with low or intermediate-1 risk myelodysplastic syndromes. *Clin Cancer Res*. 2015;21(5):985-994 (<http://www.ncbi.nlm.nih.gov/pubmed/25480830>) A dose finding study with 45 patients receiving oral study medication at 400 to 1200 mg once daily or 200 or 300 mg twice daily. MTD was not reached with once daily dosing, but 300 mg twice daily was not tolerated. The most common side effects were primarily grade 1-2 including rash, diarrhea, dry skin, fatigue and anorexia. Disease response was seen in 14 evaluable cases (32%), all but one of whom were previously treated with hypomethylating agents. Five had bilineage response and 3 of the 25 RBC- and 5 of 7 platelet-transfusion dependent patients achieved transfusion independence.
- Thepot S et al. A phase I/II trial of Erlotinib in higher risk myelodysplastic syndromes and acute myeloid leukemia after azacitidine failure. *Leuk Res*. 2014;38(12):1430-1434 (<http://www.ncbi.nlm.nih.gov/pubmed/25449687>)

In this study, 18 patients with higher risk MDS and 12 with AML received 100 mg/day or 150 mg/day PO dose of erlotinib. Generally the treatment was well-tolerated with limited non-hematologic toxicities (common grade III/IV events being skin reactions or diarrhea). The 20% overall response rate was comprised of, 1 CR, 1 marrow CR and 4 hematologic improvement. The median duration of response was 5 months.

5. Jabbour EJ et al. Outcome of patients with low-risk and intermediate-1 risk myelodysplastic syndrome after hypomethylating agent failure: a report on behalf of the MDS clinical research consortium. *Cancer*. 2015;121(6):876-882 (<http://www.ncbi.nlm.nih.gov/pubmed/25410759>)

The overall response to hypomethylating agents (HMA) was 35% with average 6 cycles and median duration of response being 7 months. Only 7% patient showed leukemic transformation while on therapy. Of the total 290 evaluable patients failing HMA, 77% remained low-risk MDS. With a 16 month follow up, median transformation-free survival and overall survival after HMA failure were 15 and 17 months respectively.

6. Santini V et al. Minimizing risk of hypomethylating agent failure in patients with higher risk MDS and practical management recommendations. *Leuk Res*. 2014;38(12):1381-1391 (<http://www.ncbi.nlm.nih.gov/pubmed/25444075>)

A perspective is provided specifically on optimizing the benefits of first-line hypomethylating agent use and on the management of azacitidine failure.

PATHOBIOLOGY:

1. Genga KR et al. Proteins of the mitotic checkpoint and spindle are related to chromosomal instability and unfavorable prognosis in patients with myelodysplastic syndrome. *J Cell Pathol*. 2015; Jan 30 [Epub ahead of print]. (<http://www.ncbi.nlm.nih.gov/pubmed/25637637>)

Immunohistochemistry for proteins, cell division cycle 20 (CDC20), mitotic arrest deficient 2 (MAD2) and the mitotic spindle kinase (Aurora B) in the bone marrow specimens from MDS patients revealed increased expression of all three proteins in patients with $<50 \times 10^9/L$ platelet count or those with abnormal karyotype. The expression level of these three proteins also correlated with overall survival rates.

2. Gjini E et al. A zebrafish model of myelodysplastic syndrome produced through tet2 genomic editing. *Mol Cell Biol*. 2015;35(5):789-804 (<http://www.ncbi.nlm.nih.gov/pubmed/25512612>)

Somatic loss-of-function mutations in TET2 gene are frequently observed in MDS which impacts normal demethylation process. Using genome editing technology to disrupt Tet2 catalytic domain via homozygous mutation, authors created a zebrafish model that was viable and fertile with normal embryonic- and at-birth- hemopoiesis, but developed myeloid dysplasia and anemia with age.

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. Greenberg PL et al. Myelodysplastic syndromes: version 2.2015. *J Natl Compr Canc Netw*. 2015; 13(3):261-272 (<http://www.ncbi.nlm.nih.gov/pubmed/25736003>)
2. Sekeres MA and Gerds AT. Established and novel agents for myelodysplastic syndromes. *Hematology Am Soc Hematol Educ Program*. 2014;1: 82-89 (<http://www.ncbi.nlm.nih.gov/pubmed/25696839>)
3. Klimek V (Ed). Myelodysplastic Syndromes. *Best Practice Res Clin Hematol*. 2015;28(1):1-68. (Special Issue with several pertinent review articles)
4. Santini V and Fenaux P. Treatment of myelodysplastic syndrome with thrombomimetic drugs. *Semin Hematol*. 2015;52(1):38-45 (<http://www.ncbi.nlm.nih.gov/pubmed/25578418>)
5. Zeidan AM et al. Current state of prognostication and risk stratification in myelodysplastic syndromes. *Curr Opin Hematol*. 2015;22(2):146-154 (<http://www.ncbi.nlm.nih.gov/pubmed/25575032>)
6. Jhanwar S. Genetic and epigenetic pathways in myelodysplastic syndromes: a brief overview. *Adv Biol Regul*. 2014, Nov 20 [Epub ahead of print] (<http://www.ncbi.nlm.nih.gov/pubmed/25499150>)

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

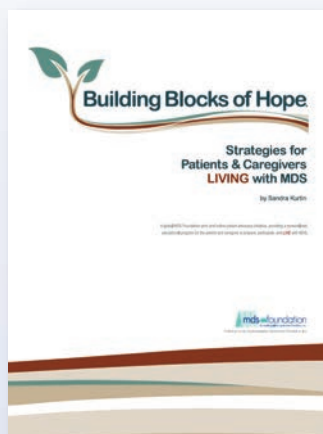
****NEW** TRANSLATED PATIENT RESOURCES ARE HERE!**

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

WHAT DOES MY BONE MARROW DO?

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

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



**Available in Chinese, Dutch, Italian, and Portuguese. Translations in Armenian, German, and French coming soon!*

BUILDING BLOCKS OF HOPE

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

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

**Available in Chinese, German, French Canadian, and English Canadian. Translations in Armenian, Dutch, French, Spanish, and Turkish coming soon!*



INTERNATIONAL MDS FOUNDATION NURSE LEADERSHIP BOARD



Erik Aerts, RN
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Angelika Bitter
Study Coordinator/Nurse
Dresden, Germany

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Florence, Italy

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Barcelona, Spain

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Hwang Chung Cheng Jordan
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Miki Iizuka, RN
Kanagawa, Japan

Jacqueline Jagger, BA, RN
Gosford, Australia

Christiane Kahle
Lead Study Coordinator/Nurse
Dresden, Germany

Meet the MDS Health Experts



INTRODUCING...

Erik Aerts

Erik Aerts, RN



MDS Center of Excellence:
University Hospital Zurich, Switzerland

Medical Specialty: Haematology/Oncology

Medical School: St. Ignatius Hospital, Breda, The Netherlands

Board Certification:

- EBMT Swiss Nurses Working Group (President)
- Past President
- International Society of Nurses in Cancer Care (ISNCC)

What led you to the nursing field?

Caring for cancer patients and their loved ones.

What interested you in hematology/myelodysplastic syndromes in general?

The large field of nursing, interdisciplinary collaboration with healthcare providers and patients, and the developments of the treatment on MDS.

What is the most gratifying part of your job?

Caring for patients with cancer, developing educational material, and teaching nurses and other health care professionals.



INTRODUCING...

Hwang Chung Cheng Jordan

**Hwang Chung Cheng Jordan, RN, MN,
Adv. Dip (Oncology) Nursing, APN**



MDS Center of Excellence:
Singapore General Hospital, Singapore

Nursing Specialty: Haematology/Oncology

Nursing School:

Nanyang Polytechnic, Singapore
University of Sydney, Australia
National University of Singapore, Singapore

Residency: Singapore General Hospital, Singapore

Board Certification:

Registered Nurse, Advanced Practice Nurse – Singapore Nursing Board

What led you to the medical field? *To help the sick.*

What interested you in hematology/myelodysplastic syndromes in general?

I enjoy the closely knit patient provider relationships, genetic and immunology nature of haematological disorders, and the ever-evolving treatment modalities.

What is the most gratifying part of your job?

The privilege of caring for each patient, and supporting them and their loved ones throughout the different phases of their treatment.



INTRODUCING...

Miki Iizuka

MDS Center of Excellence:

Shinyurigaoka General Hospital, Kanagawa, Japan

Miki Iizuka, RN



Medical Specialty: Hematology/Oncology nursing

Medical School: St. Marianna University School of Medicine Junior College of Nursing

What led you to the medical field? *I was interested in helping people ever since I was a teenager seeing a doctor for my asthma treatment. I also enjoy working with people in different occupations from doctors, pharmacists, dietitians, physical therapists, and others in order to cure and care for patients.*

What interested you in hematology/myelodysplastic syndromes in general?

There are so many MDS patients living with fear who are fighting for their treatment and convalescence which caught my attention and interest. I am delighted when I can form trusting relationships with patients who are dependent on our care, with repeated hospital visits and treatment.

What is the most gratifying part of your job? *Spending time with patients and their caregivers, and complying with their needs as much as I can from acute treatment to the end of life. I also have a sense of accomplishment when I educate patients and coach younger nurses.*



INTRODUCING...

Emily Knight

MDS Center of Excellence:

Mayo Clinic, Arizona

Emily Knight, BSN, RN, OCN



Medical Specialty: Nursing, Hematology/Oncology

Medical School: Bachelor Science in Nursing from Augustana College in Sioux Falls, SD, currently enrolled in Masters of Science FNP program at Simmons College in Boston, MA

What led you to the medical field? *I was always interested in science and working with people. I went to college and declared nursing my major from the start, and I don't regret that decision for a minute.*

What interested you in hematology/myelodysplastic syndromes in general?

No two patients with MDS are the same. It is a very heterogenous group of diseases, making it challenging.

What is the most gratifying part of your job? *Working with the patients and families who are living with MDS is by far the most gratifying part of my job. All the little things that I do in my job are all worth it knowing that patients are receiving the care they need and deserve.*



INTRODUCING...

Cindy Murray

MDS Center of Excellence:

Princess Margaret Cancer Centre, Toronto, Canada

Cindy Murray, RN, MN, NP-adult



Medical Specialty: Malignant Hematology

Nursing School: University of Western Ontario (BScN) & University of Toronto (MN)

Board Certification: College of Nurses of Ontario, Extended Class (Nurse Practitioner)

What led you to the medical field?

I have always enjoyed helping people during times of crisis.

What interested you in hematology/myelodysplastic syndromes in general?

I love the challenge (intellectually and clinically) of these disorders.

What is the most gratifying part of your job? *I like the need for longer-term relationships with patients and their families, rather than short, episodic interactions.*

Emily A. Knight, RN, BSN, OCN

Scottsdale, Arizona
United States

Sandra E. Kurtin

RN, MS, AOCN, ANP-C

Tucson, Arizona
United States

Petra Lindroos Kolqvist, RN

Goteborg, Sweden

Arno Mank, RN, PhD

Amsterdam, The Netherlands

R. Denise McAllister

MS, ARNP, AOCNP

Clearwater, Florida
United States

Cindy Murray, RN, MN, NP-adult

Toronto, Ontario
Canada

Geke Ong, RN

London, United Kingdom

Phyllis Paterson

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United Kingdom

Samantha Soggee, RN

Melbourne, Australia

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United States

Sara M. Tinsley, ARNP, AOCN

Tampa, Florida
United States

Catherine Vassili, RN

Victoria, Australia

MDS AWARENESS

SPREADING THE WORD

THE MDSF HAS A SOCIAL COMMUNITY

Join the MDSF's active social community, on both twitter and facebook.

We already consider you part of the family... Now, let's be friends!!

FIND US ON FACEBOOK



FOLLOW US ON TWITTER



PLANNED GIVING LEAVING A LEGACY

Write the MDSF into Your Will.

In addition to the gifts you give today and throughout your lifetime, taking the time to write MDSF into your will—or to make any other planned/estate gift—provides an enduring legacy of your personal interest and commitment to providing education, service, and research for those facing bone marrow failure diseases. Ask your attorney to include this paragraph, specified to your gift preferences, in your will:

I give, devise, and bequeath \$_____ (amount) or _____ % (percentage) to the MDS Foundation, 4573 South Broad Street, Ste. 150, Yardville, NJ 08620, a not-for-profit corporation for its charitable uses as directed by its Board of Directors.

It is important to remember your friends and family when drawing up a will and to make sure that all loved ones are taken care of. Once you have done this, you may wish to leave a legacy to the MDS Foundation. Leaving a legacy to the MDS Foundation is one of the greatest gifts that you can give.

Shop on AmazonSmile and Choose The MDS Foundation as Your Charity



Do you shop on Amazon.com?

Did you know that your next purchase can support the MDS Foundation?

Through the *Amazon Smile* program, charities have the opportunity to receive 0.5% of a purchase item's price. Visit the *Amazon Smile* program website to set up the MDS Foundation as your charity of choice!

As one MDS donor puts it: "I purchase a lot of things for personal and business use on Amazon. If you go to **www.smile.amazon.com** and choose the MDS Foundation a 0.5% of the purchase will go to the foundation. It's small, I know, but if a lot of people did it, it could certainly add up. Thanks!"

ORGANIZE A FUNDRAISER

Help spread awareness and support MDSF programs and services! You may want to create and organize a special event that increases awareness of MDS and the Foundation. There is no right or wrong way to do this. Design a fundraiser that fits your interests and your timelines. We are encouraging everyone to be creative and help spread MDS awareness. Contact us to provide you with MDS materials to distribute.

Have you told someone about the MDS Foundation lately? For a donation of your choice, choose from the items below as a "Thank You" for your generosity.



3 WAYS TO ORDER:

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

**RAISING AWARENESS IS YEAR-ROUND!
THANK YOU FOR YOUR SUPPORT!**

SHOWING SOLIDARITY AROUND THE WORLD

MDS Patient Support Groups Around the World Showing Solidarity on **MDS WORLD AWARENESS DAY 10.25.14** and on **RARE DISEASE DAY 2.28.15**

In the spirit of raising MDS awareness, we thank our global community of patients, patient groups and professionals supporting people **LIVING** with MDS! **ALONE WE ARE RARE – TOGETHER WE ARE STRONG!!!**



NEW JERSEY LEGISLATIVE ASSEMBLY



On January 29, 2015 the New Jersey Legislative Assembly voted unanimously to establish the last day of February as Rare Disease Awareness Day. A heartfelt **THANK YOU** to our Garden State lawmakers! We are thrilled about this recognition and are so excited to work with the Legislature and Government to improve access to treatment, increase treatment options, and make treatment and care affordable.

Spreading MDS Awareness Any Way They Can – The fight against MDS doesn't begin or end on the 28th of February or 25th of October. Raising awareness is year round!

MIAMI



ARMENIA



UZBEKISTAN



SHOWING SOLIDARITY AROUND THE WORLD

CHINA



CALIFORNIA



SPAIN



MINNESOTA



UNITED KINGDOM



GERMANY



ARMENIA



IRELAND



TAIWAN



SINGAPORE



PATIENTS & CAREGIVERS LIVING WITH MDS FORUMS

SPREADING THE NEWS WORLDWIDE

Registration Open for 2015 International Patients & Caregivers LIVING with MDS Forums

With three forums successfully completed and eleven more to go, you will find the answers, support and hope for MDS you are looking for at our FREE 2015 forums. If you've never attended one before, you won't want to miss this opportunity to meet others and to learn more about MDS, current treatments, and emerging therapies from leading experts.

For more information go to:

<http://www.mds-foundation.org/patient-and-family-forums>
and Register Now!

MEETINGS



April 18: Pittsburgh, PA
May 2: Washington, DC
June 12: Vienna, Austria
June 27: Hackensack, NJ
July 4: Yerevan, Armenia
August 15: Cleveland, OH

August 15: Atlanta, GA
October 3: Philadelphia, PA
October 24 (in honor of MDS World Awareness Day): New Haven, CT
November 7: Westwood, KS
November 14: Indianapolis, IN

AGENDA

- 9:30 am – 10:00 am Welcome/Registration — *Continental Breakfast*
- 10:00 am – 11:00 am New Therapies and Patient Treatment Options With Question and Answer Segment
- 11:00 am – 12:00 pm Quality-of-Life Session with Open Discussion
The MDS Foundation's Building Blocks of Hope Presentation – Strategies for Patients and Caregivers LIVING with MDS
- 12:00 am – 1:00 pm Lunch
- 1:00 pm – 2:00 pm Patient Support Group Open Discussion
Quick Tips for Patients and Caregivers
Nurse Led Discussion

Registration is required to attend.

Call 800-MDS(637)-0839 ext. 203 for more inquiries/reservations.





BOLOGNA AND PAVIA, ITALY
A special thank you to AIL Pazienti for their collaboration!

IN YOUR OWN WORDS

TESTIMONIALS

"I just received the Fall/Winter MDS News about a week ago. I cannot put into words how much I enjoy reading it from cover to cover, and all of the information I get out of it."

I relate to so many of the stories, and whoever is putting this together is doing a fantastic job! That's all I wanted to say. Thank you!

Marla M.

"Each time I attend an MDS Foundation Patient Forum, I learn a little bit more about MDS. The presentations are always great."

Scott M.

"Thank you all for your words of encouragement. I appreciate the education and knowledge you offer to all of us MDS patients and families. Knowledge is power. Thanks again!"

Laura T.C.

The Fall/Winter issue of the MDS News arrived yesterday, and now I have had time to take a look at it.

"I find it encouraging with the many advertisements for new trials relating to MDS."

Niels J.

"I received the MDS Foundation Newsletter and have read every inch of it —

I really enjoyed reading it!

Especially the love story. That's the one that sticks in my mind the most!

Deborah P.

"Thank you for the MDS event last Saturday in New York! I thought it was informative and interesting with an excellent combination of speakers."

The general feeling was friendly and the food was good – a very pleasant and useful day."

Lois B.

"The best and most complete handbooks I have ever read about MDS!"

I was diagnosed in June 2014 with MDS RCMD-RS. I scanned the web for information about the illness and found the MDS Foundation and your comprehensive information."

Berit S.

"Thank you so much for sending the *Building Blocks of Hope* to me. My husband was recently diagnosed with MDS."

We had not known of MDS before. I was frightened and did not know where to turn. I found the MDS Foundation website. The materials were so helpful to me and my husband. He will begin a treatment of chemotherapy soon. Thank goodness our oncologist is very knowledgeable of MDS."

Mary L.

See BBoH on page 13.



CARING AND COPING

OUR CAREGIVER STORIES

The MDS Family: Coping and Caring Luncheons

MDS patients and their families gathered at the home of Rochelle Ostroff-Weinberg, spouse of the late Robert Weinberg, for a wonderful luncheon November 1, 2014 in Wynnwood, PA. Guest speaker was Donna Cetroni, Holistic Health Nurse Counselor. We hope you will join us at our next gathering on Saturday, April 25, 2015 at the White Dog Café in Philadelphia. Kindly register by April 17th by calling 1-800-637-0839 or email ahassan@mds-foundation.org.

Coping and Caring Luncheon, Wynnwood, PA



"Being given this opportunity to share openly one's experience, amongst others who thoroughly relate, promoted a non-stop flow of personal anecdotes and stories from the heart. The group mingled beautifully; it was an emotional group which is good — that is why we are organizing this program. Donna was superb. Warm soup, cider and other warming delectables shooed away the rain and cold."

— Rochelle Ostroff Weinberg (Luncheon Host)

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

"It was my pleasure and honor to be amongst most beautiful people in your amazing home. I especially appreciate your gift for gathering with warmth, love, style, and especially grace. This experience supports my most inner belief that healing is possible. I am a friend of people affected by MDS. Thank you for allowing me to be with your vision to provide a healing space for those on this path."

Donna Cetroni, RNC, CPHQ, AHN-BC, MA (Guest Speaker)

"Thank you for this great time to share." – *Ron S.*

"Glad to hear stories from others in the MDS Community." – *Jeff and Amy L.*

"Lovely meeting everyone and hearing everyone's stories." – *Chanda M.*

"Informative, great food, and wonderful company. Looking forward to many more get togethers." – *Eileen R.*

"This has been a great enlightenment and education. Thank you for all your hospitality and good food."
– *Paul F.R.S.*

"We enjoyed our day immensely! We'll plan to come again!" – *Flossie R.*

"These patient forums are extremely helpful. Just the interaction coming from those with MDS is worth the trip. Rochelle is to be commended for continuing Bob's legacy. God loves you and so do we!" – *Charles R.*

"It was interesting and good to meet others with the disease. It was great to see other MDS patients who lived longer with MDS, as well as meeting another widow as a bond with someone living through the same experience." – *Tania A.*

"It was great to share and experience with others who are living with MDS. It was hopeful to see others still living a good quality of life with MDS. And it was great seeing my mother bond with others with the same experience." – *Jimmy W.*

GET ANSWERS & SUPPORT

MDS PATIENT MESSAGE BOARD

Whether you are a patient, spouse, caregiver, family member or friend; newly diagnosed or have lived with myelodysplastic syndromes for years, thanks to the internet we have something for you. The *MDS Message Board* is a discussion site where you can ask questions, get answers, or give answers. We hope that you will find this to be a very valuable resource in your journey **LIVING** with MDS. We have recently revised the format of our forum to be much more user friendly. We are encouraging everyone to go online at <http://www.mds-foundation.org/forums/forum/patient-message-board> to sign up, browse and join in the discussion!

www.mds-foundation.org/forums/forum/patient-message-board



MESSAGE BOARD

Review answers to commonly asked questions or get answers to **your** questions from an MDS expert

MY JOURNEY IN MDS CAREGIVING

Sandra Madden

"I can help you with a loan? How much do you need?"

"Do you need a place to stay? For a week? A month? A year?"

"I'll take care of you."

This man cared. I never heard him speak ill of another human being. He constantly gave to friends and strangers; his money, his heart, his talent. Throughout his life he was a care giver in the truest sense. And during his lengthy illness, he taught me how to be a caregiver.

My husband was a comedian, not the living-room variety, but a true professional. Dave earned his living as a stand-up comic and then television actor. His name was Dave Madden. But most, especially the boomer generation, remember him as Reuben Kincaid, the put-upon manager of the "Partridge Family" television series. I can't count the number of times fans approached, calling him, "Mr. Kincaid." And thanking him "...for the gift of laughter."



Dave Madden



But Mr. Kincaid was only a role Dave played.

Dave was a regular on the first season of "Laugh-In." He was a lead performer on the "Camp Runamuck" television series and performed as a regular for seven seasons on "Alice."

Despite numerous guest appearances on the iconic television programs of the 70's such as "Love Boat" and "Barney Miller," Dave is still remembered as Reuben Kincaid. For twenty years he played the role of Barnard Walton on the Odyssey radio program sponsored by Focus on the Family. He was featured in innumerable dinner theater performances and countless voice-over commercials, and yet... Reuben Kincaid is the character audiences remember fondly.

But the man I knew was a kind, generous man. He made everyone he met feel special. And he gave the gift of laughter. Always.

Dave and I met in college when we were both studying at the University of Miami. At that time UM boasted one of the few broadcast/communications schools in the country. Dave had served in the Air Force and was attending school on the GI Bill. He was older than me and two years ahead in school, so although we'd dated, we went our separate ways when Dave graduated. Following my graduation, I became a broadcast writer, writing radio commercials and station promotion campaigns in Miami and Los Angeles before moving on to writing and producing

local PBS programming in Miami. I also did voice-over work on the side and my old college friend and I met in Los Angeles sound studios from time to time. By then, with some dating experience behind me, I considered him one of the nicest men I had ever known. But I obviously did not light his fire again on these chance occasions!

We had been married (to others), had two children each, and were divorced when we met again in a social setting at the home of old college friends. After a long-distance courtship, I was living in Miami, Dave in Los Angeles; we looked hopefully to spending our Golden Years together.

When we married, Dave was sixty-six years old and had type 2 Diabetes, a very treatable disease. Over time he developed a heart condition known as A-Fib. But these were treatable conditions and we looked forward to reasonably healthy retirement years. I began writing historical romance novels and Dave retired from voice-over commercials. We were free to travel and we did! We joined friends and embarked on cruises all over the world from the British Isles to the Baltic to Bermuda.

We made a major move from Los Angeles back to Miami. I missed my family and desperately wanted to be near my grandchildren. It was a good move as we had many mutual friends from our college days who still lived in South Florida. When my son-in-law was relocated, we followed my daughter, her husband, and two children to the Jacksonville, Florida area. My son and his children lived in Florida's panhandle so we were able to enjoy full, happy houses during holidays and family celebrations. As much as possible we flew Dave's children in from their respective homes in Los Angeles and Oregon.

Life was good. Until, the "weakness" set in.

Whenever a doctor asked Dave what happened, why he had fallen, he replied that he'd felt weak. Fortunately, Dave never broke any bones with his falls. From the first EMT and hospitalization there was always a

OUR CAREGIVER STORIES

little something to pin his collapse on—a bit of pneumonia, a touch of congestive heart failure, a virus, and always inflammation. Plus something new, anemia. Anemia became the new constant. He began to receive shots of Procrit or Aranesp.

Neither of us had any idea what would follow for the next five years. Little did I understand at the time that my caregiving journey had begun. I started carrying a pocket calendar to record hemoglobin counts and medication instructions. By the end of our journey I'd graduated to a large orange loose leaf binder. The notes and medication information became increasingly important as I shared them with doctors, nurses and hospitals in the days ahead.

Dave told everyone and anyone who asked about his health that he had a "mystery malady." He claimed that none of the doctors knew what was wrong with him. And they didn't for a long while. He went to just about every specialist known to the medical community; infectious disease, rheumatologist, neurologist, nephrologist, hematologist/oncologist and of course our primary physician.

Dave entertained in every specialist's waiting room that had more than two people waiting for their appointment. He pushed his walker into the room, took a seat and proceeded to perform his stand-up sitting down. He didn't need a microphone to be heard. Was I ever embarrassed by his waiting room stand-up? Yes. But I always admired his gift for making people laugh... especially on those days when he could barely stand.

My mother, a former nurse, told me from an early age that I could never be a nurse. She let me know in no uncertain terms that I did not have what it takes. Well. You do what you have to do and the more you do it the better you get. Although I did go by the name of Nurse Ratched at home. Dave loved his movies and knew Nurse Ratched as the infamously nasty, incompetent nurse from "One Flew over the Cuckoo's Nest." My husband understood I wasn't the nurse



and nurturer that I would have liked to have been. But I did my best. And, honestly, I was never as bad as Nurse Ratched!

Dave was a big man—six two and two hundred thirty pounds at the start—and when he fell, or could not get out of his chair, I didn't have the strength to lift him, which meant a 9-1-1 call. A call he came to dread, knowing it would lead to being in the hospital for a least a week, followed by one week, up to two, in a rehab facility. And then home health care upon release. (He did attempt an escape from the first rehab facility... but that's another story and another caregiving episode that most people will never face. I hope. Unbeknownst to me, I was driving the getaway car!) When an EMT recognized him as happened sometimes early on, he felt compelled to keep smiling and joking all the way to the hospital.

Days turned into weeks, weeks into months and years of decline. When I woke in the morning, I would lie in bed summoning patience and strength, stare at the ceiling and ask myself: What kind of day will this be? Will it be a hospital day? A doctor day? An emergency room day? A Procrit day? A transfusion day? Or just maybe a near-normal day? I would listen for the sound of his walker and know it was time to rise and shine.

Dave's hematologist/oncologist and nephrologist became the two doctors he saw the most. Sometimes we were in

doctor's offices three, or four times a week. Dave never admitted to any illness except "weakness" and he refused to discuss his illness—or anyone else's! Unlike many patients who asked questions and searched for answers, my husband was strangely indifferent.

When a doctor asked him a question or requested information, Dave directed him or her to me for an answer. This must have been frustrating for the doctors. And sometimes I felt embarrassed. But fortunately, I kept records. Because Dave was definitely not interested in being sick.

Eventually we discovered his anemia stemmed from a failure of his bone marrow. Dave's bone marrow had stopped manufacturing the needed number of healthy red blood cells—the cells which carry oxygen throughout the body. Little by little the injections of Procrit and the dosage of the drug increased. When Procrit was no longer effective, Dave's red blood cell transfusions began. At first the difference was dramatic. He rallied. But then, as the need for transfusions increased, his hospitalizations increased. His weight continued to drop which he blamed on his "hospital diet."

During my journey with Dave I learned how to be a caregiver by trial and error.

I learned that caregiving means exercising a bit of psychology. To have goals. I continued to plan cruises at the beginning. Dave enjoyed the meal times

OUR CAREGIVER STORIES

when he and his longtime friend would perform magic for our table companions. (He was an accomplished magician and member of the Magic Castle in Los Angeles.) He used a scooter to get around the ship and was able to continue his hobby of photography, shooting an amazing number of pictures from the decks. The goals might be big or small, just to have something to look forward to... whatever it might be, a movie, a dinner out with friends was important to Dave—and his caregiver.

For twenty years Dave wrote a holiday letter but in 2010 announced it was his last one. This seemed to me like a step toward giving up so I encouraged him to write another even if he had to start writing it in October.

This excerpt is from his 2012 holiday letter which he wrote in outline form:

- *Hospitals: 3 sessions in 2 hospitals, lost 40 pounds. Hospital food. They should put out a cookbook.*
- *Rehabs: 3 weeks in various rehabs. Looking for Hollywood starlets. No luck.*
- *Incidental info: My mystery malady... Florida doctors having a convention and naming it after me.*

From his 2013 Holiday Letter...

- *I set a new record in 2013, only ONE visit to *** Hospital. They shudder at my presence. They know I'm only there to rate the food. Have you ever tasted hospital food?*
- *I figured as long as I was at the hospital, I may as well have my lungs drained. It was the only part of my anatomy they hadn't fiddled with. They removed 3½ liters of fluid. My own fault... I never should have taught my lungs to swim.*

I learned that caregiving means learning a new language. I learned the meaning of new medical terminology: pleural effusion, interstitial fibrosis, mixed connective tissue disease and more. And I learned to build relationships with the doctors responsible for Dave's day-to-day care.

I learned that caregiving means taking a break. Over the four and half years of Dave's illness, I left him for occasional



family events and once took a ten day vacation. While I was away Dave's companions were my friend, a nurse, one of his long-time friends who came in from out of town to stay with him, as well as Dave's daughter and my daughter and son-in-law. The support of friends and family was invaluable. I can't thank those who spent time with him enough, in the hospital and at home for their companionship.

When I returned from breaks I felt like a new person. My patience and energy had been miraculously restored. Dave always encouraged me to "go." Only once did he call me back.

I also learned that as a caregiver I needed to do some bookkeeping. Keeping track of drug dosages, when and where to administer them, and how much was vital.

I learned that caregiving is running the gauntlet of emotions. There were times I felt frustrated, angry, out of patience and exhausted. I felt sympathy; I felt his pain and marveled at his patience. Although I knew from what I'd read these were normal emotions, I also felt guilty when I was impatient. Yes, there even were times when I felt overwhelmed and resentful.

I learned caregiving requires strength. Physical strength—I told myself I was building upper-body strength, lifting and storing his transport wheelchair and walker. I also needed to be emotionally strong to be able to deal with whatever a new day held in store.

Caregiving is an epic task. You do it because you love your husband, wife,

mother, sister, father, brother or friend. And may I mention here that the casts of television series in the 70's were not paid anywhere near what today's TV casts earn? The residuals came in cents rather than dollars. Only once, did we hire extra nursing help.

I did not know about the MDS Foundation when my journey with Dave and MDS began. I wish I had. Recently one of my long-time friends was diagnosed with MDS. Her platelets are involved. What are the odds that a rare disease would touch two people I love?

By the time I heard of her diagnosis, I knew about the MDS Foundation and its excellent work. I called and asked what I could do to help. I may not possess many skills, but the least I can do for Dave and my dear friend is to help create awareness... but I hope I can do more.

In the end, caregiving is taking it one day at a time. Not looking back, not looking forward.

In January 2014, Dave eagerly signed the papers that would allow him to enter Hospice care and leave the hospital. He was given two units of blood before he left and when his children came to say goodbye a day later, I don't think they believed he was deathly sick. With the aid of the fresh blood he managed to put on the performance of his life. But after they left, five days later, he began to drift into sleep more and more.

My daughter and I were at his bedside when Dave passed quietly away. Along with the sorrow, I felt shocked. He'd rallied so many times before that subconsciously I think I believed he'd rally once more.

But Dave will always be with me, with all of us; family, friends and fans alike. The tapes and reruns of "The Partridge Family" and his many other programs continue. He can be seen most any day, still giving... the gift of laughter.

"As you are probably aware...I'm not well. I've taken so much penicillin that every time I sneeze I cure someone."

— Dave Madden from his stand-up monologue, 1962

The Power of Glinda

Elizabeth Fenik

East Greenwich, Rhode Island

Here are 7 things I'd tell my younger self:

- Believe in yourself
- Keep going no matter what
- Embrace uncertainty
- Learn that it's ok to be uncomfortable
- Connections are what matter
- Listen to Glinda

This is the story of how I came to believe these things, and more importantly what came after.

In 2004, after a brief, but serious illness I had the worst day of my life. I was diagnosed with MDS, an often-fatal pre-leukemia disorder of the bone marrow. Knowing that I could very well die from this I was instantly overwhelmed with regrets. I had wasted so much time living in fear and being stuck.

I was paralyzed in my life, afraid, unhappy, unhealthy; an overweight smoker. Then while being treated for MDS, a medication caused my spleen to rupture and the operation to remove it almost killed me. I was put into a medically induced coma in order to heal and was given a 3 week time-out from life.

I awoke to find some things had changed and some things sadly had not. I was suddenly a non-smoker and had lost 30 pounds, but I still had cancer and we hadn't even begun to deal with that.

I was scared — no, I was terrified. Every minute it seemed as if there were a choir in my head screaming “you're going to die”. My only relief was to drown them out by playing Aerosmith at full volume through the headphones. I was faced with and lived through months of limbo, my moods dictated by my endless blood test numbers, my weeks filled with doctor visits and all day blood transfusions, and most of all the fear that none of this would be enough to save me. Emotionally I felt completely disconnected from the universe. as if all of creation had turned its back on me and I had been banished. I have never felt so alone.



*Betsy & her donor in 2012
(7 yrs. post transplant)*

I spent a lot of time thinking of all the things I might never do

- Would I live to see the age of 50?
- Would I grow old with my husband Cliffe?
- Would I die and leave my parents heartbroken and defeated?

I certainly would never make it back to Italy where we had just purchased a home — our dream come true.

The list went on and on.

Somehow, one day at a time, sometimes 5 minutes at a time, I kept going. I guess I didn't know what else to do. My husband, parents and friends propped me up and showered me with love and sometimes I only kept going for them. They believed that I would recover so I needed to believe it too.

We tried to do normal things. Dinner out, vacation, celebrated birthdays, kept living, and the days passed one by one, very slowly. I bought a new camera and taking pictures was another way I could keep my mind from racing to that bad place of certain death. Having too much time on my hands I also thought about what I would do if I did indeed survive. I knew that given a second chance I would never take life for granted, nor would I waste a single second being stuck and afraid. I would really LIVE if only I could live.

By the late fall — 9 months later — we found out that the MDS had become leukemia. My bone marrow was not going to repair itself and my only chance was a risky bone marrow transplant. This procedure involved severe chemotherapy that would kill my bone marrow, leaving

me without an immune system — and if my donor's cells didn't take I was screwed. I'd be locked up in that isolation room until I died of an infection.

This all seemed so huge and scary. It was weird science to me, like a dream or a movie of someone else, but it was a plan. It was taking action, fighting what I knew had been coming all summer. It was time to do battle, and although terrified, I knew it was my only chance and that I had to trust my doctor. More than that, I had to believe in myself. Believe that I could heal, believe that I would recover, and that there was a reason for me to stick around. There was a place in the universe for me.

I wasn't at all sure of what that place was or who I would be, but I began to feel more comfortable with the uncertainty. Not that I was actually embracing it, but discomfort was beginning to be less awful now that we were in the fight. I knew that only by risking it all, by crossing the point of no return could I recover and begin again. This big, scary plan was certainly better than the limbo in which I had existed for nearly a year.

So between January and late June, I:

- had a bone marrow transplant
- physically went to hell and slowly came back
- spent 5 weeks in the isolation unit of the hospital and 5 weeks in a cool apartment next door to the hospital
- lost all my hair
- rocked the bald, masked, gloved, with big earrings look
- came home and continued the slow recovery from near death
- bought a new car — can you believe they gave me a 5 year loan???

I also began planning to do the things on that list I made the first few days after my diagnosis. I felt so lucky to be alive and traveling again. We went to our first NASCAR race and I, having been a closet car racing fan for years, loved every minute of that show. We made it back to Italy. We reconnected with friends, and life began to take shape again piece by piece.

I knew that I didn't want my old life back, that fearful, stuck existence. I wanted



Photo of me in the hospital

adventure, growth, expression and a real connection to the universe and others. Like Maya Angelou said “The need for change bulldozed a road down the center of my mind.” I started therapy and began a journey to discover the reasons I was so afraid of life. Again, it was a big, scary undertaking but hey—I’d just survived a burst spleen, a coma, 9 months of mental, physical and emotional torture and a bone marrow transplant, so this surely wouldn’t stop me. I was using what I’d learned about my strength and grit to get me through the next challenge. Besides, I’d already come so far and invested so much I couldn’t quit. Anytime I felt like it was too much I’d think this is nowhere near as bad as my worst day, and I got through it.

But physical and emotional recovery were only the start. I wanted to really LIVE. In capital letters. I wanted to pursue my lifelong hobby of photography in a much more serious way. My new camera was my tool and I threw myself into making photos with wild abandon. Photos that no one ever saw because I cared so much about my art that I couldn’t bear the thought of rejection. I made thousands of images, poured over them and then put them safely away. I told myself that they were just for me anyway, but down deep I knew that I wanted to launch them into the world and share them with others. Once again, fear and discomfort were holding me back.

Then a friend told me to hang out with my own tribe (artists), and that my life was a story and I should be the hero. I had never thought of it that way, but I realized that it WAS my story. I was writing it and I pretty much controlled what was next and how I would live it. The uncertainty of what would happen was fine because

whatever it was, I’d always have me. I was scared, but that’s because this was another big plan, but I knew that I was getting good at big plans. My discomfort meant that I was learning and growing. My fear told me that my plan was plenty big. And besides, nothing would ever feel as bad as my worst day.

So I made and published a website of my photographs, entered some in local art shows, and went back to school at Rhode Island School of Design taking photography, digital media and printing courses. There I met other photographers and began hanging out with my tribe, eventually joining them on a photographic delegation to Cuba this past January.

In the beginning of 2014, having been cancer-free for nearly 10 years, I set some intentions for the year aimed at pushing myself and my boundaries. I would say “yes”, not “no” to things. I would take risks, investigate uncharted territory, and seek what’s next. But the most important is this: You don’t need a diagnosis to spark the changes you desire. You don’t have to nearly lose everything to gain your true life. All you need to do is...

- believe in yourself
- keep going no matter what
- embrace uncertainty – that’s where the growth is
- know that you will be uncomfortable and that’s ok
- welcome fear – then you’ll know your plans are big enough
- get connected to your tribe and the universe and,
- remember as Glinda said, “You’ve had the power all along, my dear you just needed to learn it for yourself.”



One of my photographs from Cuba – my new life as a photographer

From Patient to Advocate

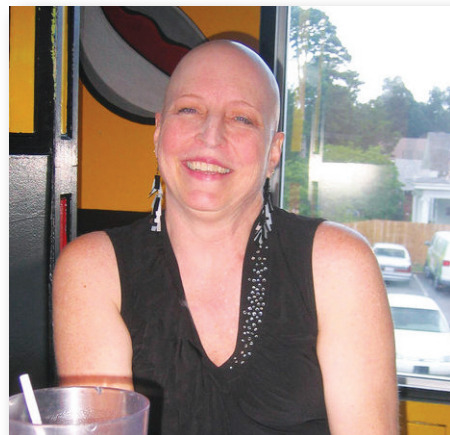
Brenda Hawkes
Fenton, Michigan

In 2006 I was a busy person, too busy to even go to the doctor to check a lump in my breast. I didn’t have time to be sick. But, I was sick, very sick.

At age 46, I was diagnosed with stage 3B triple negative breast cancer. I was afraid, worried and mad. Although I couldn’t feel it, the cancer was there and we needed to treat it aggressively — and fast.

Over the next six weeks I lost my breast, my hair and my job.

At the time, I was working for a nonprofit. When I shared my diagnosis, the board of directors asked me to step down from my position. But I was not going to go easily. I thought my life was my work. I thought my job was my identity.



My oncologist gave me some advice that changed my life. It went something like this: “Brenda, you are not your job or your public position. You are so much more. And you will get through this cancer journey to go on and prove those people wrong.”

Each of us starts this journey at a different place but we do share some of the same emotions, stresses and fears. My chemo was hard on me; the fatigue and aches were the worst. I remember days when I couldn’t even walk up the stairs to the bedroom.

As I was finishing the chemo rounds, my doctors and I decided to have a genetic

test to check for the BRCA1 or 2 gene mutations, which could raise my risk of developing breast cancer again. It turns out I carry the BRCA1 mutation. That was another tough blow to me and my family. I had a hereditary risk that came from my father's side. I also had the risk of passing the gene mutation to my children. That is a hard reality to deal with.

I finished chemo and then had radiation, followed by eight more surgeries during the next few years. Some of those surgeries were preventative, like a second mastectomy and removal of my ovaries, prompted by my BRCA1 gene. It took a long time for me to get well and to get back to some sort of regular life again. I often think that getting back to a healthful place was as hard as the actual treatments.

Recurrence or secondary cancers like myelodysplastic syndrome (MDS) were concerns as well. Robin Roberts announced on "Good Morning America" that she was diagnosed with MDS after her treatments for triple negative breast cancer—the same type I had. What I don't know or understand is why Robin developed MDS after her treatments. But this was a reminder to me that I needed to continue to focus on my health and well-being even after my treatments ended.

Not only am I a nine-year cancer survivor, but I also took on the role of caregiver during my husband's colon cancer journey. He was diagnosed in 2002 with a rare colon cancer. He, too, endured surgeries and chemo. It is almost harder being a caregiver than a patient because you can't fix what is wrong with your loved one. And if the patient is stubborn—like my husband or me—it can be even more difficult. Today, we are both well and living healthy lives.

It is these experiences that have led me to my new profession as a patient advocate. I am fortunate to have a career working with people across the United States to educate them on resources but also to lend a shoulder to lean on or give a hug.

I joined the staff of Diplomat, a specialty pharmacy, in 2011. Since then, I have had the privilege of working side by side with some of the most caring and committed



people in the health care field. Let me explain a little more about Diplomat and our unique position in the industry.

WHAT IS A SPECIALTY PHARMACY?

A specialty pharmacy isn't the traditional corner drugstore. Instead, it focuses on providing treatment for those with long-term and chronic conditions and illnesses. For those living with complex conditions—including cancer, bleeding disorders, HIV and hepatitis C—the therapies needed require special instructions, handling and administration. That's where a specialty pharmacy becomes part of the health care team, working together with physicians, patients and caregivers to provide specialty pharmaceutical care and personalized therapies to support the management of complex drug regimens.

These specialty medications and treatments often come with high costs. At Diplomat, we believe a patient should never have to choose between paying for groceries or affording their medication. If we find coverage leaves a gap, we connect patients with foundations or copay card programs to help lessen the out-of-pocket amount patients are responsible for. In 2014 alone, Diplomat connected patients to over \$55 million in copay assistance from third parties.¹

Support doesn't end when the prescription is filled. Diplomat offers hand-in-hand support at every step of a patient's journey. That's why we have a clinical helpline available 24/7 with pharmacists and nurses ready to answer patient

questions, even when the doctor's office is closed. We also may reach out to patients during the course of therapy to check in on how they're feeling and help them deal with any side effects.

A PATIENT ADVOCATE

Diplomat also reaches out to patient advocacy groups and organizations for greater understanding of how to support our patients. That's where I come in.

As the manager of patient advocacy at Diplomat, I attend meetings across the country, talking to patients, caregivers and advocacy leaders to learn about their needs and share resources and support from Diplomat. These educational support meetings are focused on many conditions, including multiple myeloma, MDS, breast cancer and prostate cancer.

One of my favorite things is having the chance to speak with patients face to face. It is a privilege to support patients on their own journey and share in furthering the mission of a company that strives to provide the highest standard of care. These interactions, experiences and relationships impact every facet of Diplomat's operations. Our patients are at the heart of all that we do, stemming from our core tenet: "take good care of patients, and the rest falls into place."

When I was first diagnosed, I never imagined I'd be in the position to help so many patients live their best, healthiest lives. My oncologist was right; I did make it through and I'm here to help others do the same.

To learn more visit: diplomat.is/advocacy

Email: hello@diplomat.is

Or find us online on Twitter, Facebook or LinkedIn at @diplomatr

1. Diplomat Funding Report, 2014



Thankful...

Joe Nucera
Forest Dale, Vermont

I would like to dedicate this to Bonnie, who I call my “wonderful wiser half.” She has been with me since before I was diagnosed. She is my best friend and I love her very much, she is the greatest care giver, and she put ups with me... I would also like to dedicate this to Dustin Kutzner, who gave me my second chance at life.

Also to my transplant team at Dartmouth Hitchcock Hospital, Doctor Hill, Doctor Lowrey, Doctor Meehan and Susan Brighton, and last but not least, my favorite, Lynn Root, RN, blood and marrow transplant nurse coordinator. To the staff on 1 West who were superb in taking care of me in Dartmouth, and also the staff at Rutland Foley Cancer Center.

I am from central Vermont where the rain comes and the grass grows quickly and you must mow it quite often. When I was mowing I could feel I was getting short of breath and having some abdominal pain. After a few times of this happening, I took the advice of “my wiser half” and went to my primary care doctor, Dr. Dabbs. He took a couple of blood tests and made me come back the next day for another round of blood tests. I was wondering why he was taking so much blood. When we were done he told me I needed to go see an oncologist at Rutland Regional Medical Center. When I arrived at the hospital the oncologist told me my blood counts were a little out of whack. It was in Rutland Regional where I had my bone marrow biopsy. When the results of the biopsy and all the blood work showed I had MDS, the doctor set me up with an appointment at Dartmouth Hitchcock Medical Center in New Hampshire. There I met with Dr. Hill and Lynn Root. They told me I had MDS and I needed to start chemotherapy. Dr. Hill and Lynn explained everything to myself and Bonnie. They left no stones unturned. I was in a state of shock to be honest. Bonnie and I talked about all of this during our one and a half hour ride home. Was I scared? You bet I was... I started my



chemo treatment in the Foley Cancer Center of Rutland Regional Medical Center and it was there they put in my first port. Next came the Central Line that was put in at Dartmouth. From the time I walked in, the staff was so nice and personable and explained everything to me about the whole chemo process — which put me at ease. I got to know all the nurses and staff and they were so good. There were many times when I had blood transfusions. One time I was really depressed. I felt like I was taking a chair away from another person who was sicker than me. Susan, my RN that day, sat me down and helped me through the depression.

After staying in the hospital up to a month, I kept a smile on my face. I would get a mask and leave my room to walk inside or outside. They started calling me the poster man for 1 West. Lynn kept looking for a donor for me, meanwhile I still kept a smile on my face and Bonnie just helped me through all of it. After some treatments that didn't work, it was time to

get a donor. Lynn worked tirelessly, as she does for everyone, to find a match — and she did. My donor had to go thru a lot of medical tests himself. When I got the call from Lynn she said, “It's time, Joe”, and I had full body radiation. On January 16, 2013, I had my transplant with more people in my room than you can imagine. The transplant came from someone overseas. After the transplant my counts did not go up as fast as I wanted them to, so I was getting a little crabby because I missed my home. Finally the time came and I went home!!! I thought I could just go back to my everyday life as it was before my transplant. Boy, I was wrong. I felt elated to be home but I had to stay away from crowds for about a month. I was weak and there were some days I was nauseous, but I got thru it with the help and support from Bonnie and all my friends.

I know now that my donor was from Germany. I had to wait for 2 years for that information. Once the time finally came, we emailed each other after Lynn got the information for me. He is young, and God bless him for being so unselfish and going through all the needed tests and time that it took to save a stranger's life! I owe my life to this young man!

I know I skipped a lot, but if you have a great attitude, a smile on your face and much needed support, all will be fine — as with me. To end this, God bless you all — especially the donors. Without them we couldn't have ended up this way!!!



Bonnie, Dr. Hill, (Director of bone marrow transplant team), Lynn Root, (blood and marrow transplant nurse coordinator), and Joe.

Juliette's Journey of Healing and Hope

Marti Jaenki
Helen, Georgia

Juliette was given to us by God on July 9, 2003 – the daughter of Marti Jaenke and Ryan Lyng. Juliette is now 11 years old and she was born with two rare conditions – Pierre Robin Syndrome and Moebius Syndrome. Pierre Robin Syndrome is a condition of facial abnormalities with the main features of a cleft palate, small lower jaw and chin and microstomia (small mouth). Moebius Syndrome is a rare neurological disorder that primarily affects the 6th and 7th cranial nerves of the face.

In April 2014, Juliette was diagnosed with Myelodysplastic Syndromes (MDS). At this time she was in the 97% range for developing leukemia along with the diagnosis of MDS. In August 2014, it was discovered that Juliette has fibrosis of the bone marrow (scarring of the bone marrow), which made her at higher risk for engraftment failure. Juliette entered Children's Healthcare of Atlanta at Egleston Hospital on September 8, 2014 and began her chemotherapy in preparation for the cord blood transplant to follow. Juliette's cord blood transplant was mid-September and several weeks following the transplant, her white blood cell count continued to drop. As time went on through September, her doctors became very concerned that the cord blood transplant did not graft. And on October 29, 2014, we were informed that Juliette's transplant had failed. Juliette was placed back on the National Bone Marrow Registry in hopes to find an immediate bone marrow match. A match was quickly found, however, the match found was for a Peripheral Blood Stem Cell Transplant which is rarely used on children. Her team of physicians decided that this must be done as soon as possible because of Juliette being at high risk for infections. Her second bone marrow transplant was performed on December 18, 2014. The peripheral blood



stem cell transplant has a high risk of developing acute and chronic Graft vs Host Disease. Knowing this was such a big concern, her team of physicians really had no other options at that particular time.

As time progressed through the next month, we all had high hopes that she wouldn't develop the GVHD. However, in mid-January Juliette started to become very ill with the symptoms of GVHD. She was diagnosed with acute GVHD, Stage 4. Juliette developed a fungus in her lungs, the BK virus, blood clots in her kidney and bladder and the Adenovirus. At present, she is still suffering with the BK virus, Adenovirus and GVHD. She has been on some experimental medications, along with the treatment of Extracorporeal Photopheresis, which she no longer takes because of side effects of internal bleeding and other harsh side effects. Juliette has been removed from some of her medications in order for her body to rest for the next few weeks. Her Bone Marrow Team of Physicians will be placing her back on immunosuppressant drugs to try and get control of her GVHD that has now invaded her skin and digestive system.

When Juliette was diagnosed back in April, 2014, little did we know what we were facing. The day before she entered the hospital she was an average 11 year old little girl that dreamed of life and enjoyed being able to be with family and friends. She went on trips with family, working at the family business, spending time with her

siblings, going to school, playing softball, fishing, swimming and visiting grandparents. Once she was admitted to the hospital, life started to have a different outlook. Her dreams of her childhood and the fun that was had during her 11 years quickly turned to challenges such as: chemotherapy, nausea, vomiting, isolation, catheters, IV & medication poles, transfusions, hair loss, loss of appetite, loss of energy, mood swings, therapy dogs and her new found friends which are her incredible nurses and doctors. Juliette has gone through two bone marrow transplants, too many to count blood transfusions, four Pediatric ICU visits, isolation, an experimental drug and many hours of long suffering. She has been in the BMT Unit for 7 months now and will continue for many more months until she is healthy enough to leave. Once she is dismissed, she will be recovering at the Ronald McDonald House in Atlanta for three months.

Juliette is a very strong-willed, funny, silly and adventurous 11 year old little girl. The best "Prankster" she loves to plan and play tricks on family and friends. But most of all she is courageous, strong, brave and heroic, and possesses a positive attitude.

If you would like to follow along with us as we travel through Juliette's Journey of Healing and Hope, please visit:

www.facebook.com/julietteshealing



SPECIAL ANNOUNCEMENT



PRESENT



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

OUR CAST



Sean Patrick Flanery



Quinton Aaron



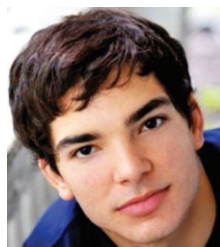
Matthew Rauch



Valerie Cruz



Katya Martin



Juan Castano

THE STORY

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

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

Get YOUR digital download or Pre-Release DVD today!

www.mylastchristmasthemovie.com



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.

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PRESS RELEASES

DECEMBER 8, 2014 – *Results from Phase III Study of REVLIMID® (Lenalidomide) Demonstrating Improved Transfusion Independence in Patients with Rare Blood Cancer, Non-Del-5Q Myelodysplastic Syndromes (MDS), Presented at ASH.*

Median duration of transfusion independence was 8.2 months

SAN FRANCISCO (BUSINESS WIRE)

Celgene Corporation (NASDAQ:CELG) today announced results from an international phase III study of REVLIMID® (lenalidomide) compared with placebo in patients with red-blood cell (RBC) transfusion dependent low-risk myelodysplastic syndromes (MDS) who were unresponsive or refractory to erythropoietin stimulating agents (ESA) and did not have a deletion 5q cytogenetic abnormality. The results were presented during the 56th American Society of Hematology (ASH) annual meeting.

The study, presented by Valeria Santini, MD, found that significantly more patients treated with lenalidomide achieved RBC-transfusion independence of at least 56 days compared with placebo (26.9%, [43/160 patients] vs. 2.5%, [2/79 patients]; $p < 0.001$), the primary endpoint of the study. The majority of patients (90%) with transfusion independence responded within 16 weeks of treatment. For patients who became transfusion independent, the median duration of transfusion independence was 8.2 months (range 5.2–17.8). Additionally, transfusion independence of at least 168 days was reached in 17.5% (28/160) of patients receiving lenalidomide compared with no patients receiving placebo. The incidence of AML progression (per 100 person-years) was 1.91 (95% CI 0.80–4.59) and 2.46 (95% CI 0.79–7.64) for lenalidomide and placebo patients, respectively. The follow-

up period was not long enough to permit an overall survival comparison.

Myelosuppression was the main adverse event (AE). Grade 3–4 neutropenia occurred in 61.9% versus 12.7% in the lenalidomide and placebo groups, respectively, and grade 3–4 thrombocytopenia occurred in 35.6% versus 3.8% in the lenalidomide and placebo groups, respectively.

“This confirmation of the Phase II data is extremely encouraging. Based on this study, REVLIMID may offer this refractory patient population an additional option beyond their current limited choices,” said Guillermo Garcia-Manero, MD of the M.D. Anderson Cancer Center at the University of Texas.

REVLIMID is not indicated for the treatment of non-del5q MDS in any country.

Source: Press release, 12/08/14

<http://ir.celgene.com/releasedetail.cfm?ReleaseID=886614>.

MARCH 30, 2015 – *Novartis announces FDA approval for Jadenu™ to simplify treatment administration for patients with chronic iron overload*

- *Jadenu (deferasirox), a new formulation of Exjade (deferasirox), is the only once daily oral tablet for iron chelation*
- *Jadenu, taken with or without food, simplifies daily treatment administration for patients with chronic iron overload*
- *Chronic iron overload is a serious condition that can affect people with sickle cell disease, thalassemia and myelodysplastic syndromes*

BASEL: Novartis announced today that the US Food and Drug Administration (FDA) has approved Jadenu™ (deferasirox) tablets, a new oral formulation of Exjade® (deferasirox) tablets for oral suspension, for the treatment of chronic iron overload due to blood transfusions in patients 2 years of age and older, and chronic iron overload in non-transfusion-dependent thalassemia syndromes (NTDT) in patients 10 years of age and older. Jadenu is the only once-daily oral iron chelator that can be swallowed whole.

Many patients with sickle cell disease, thalassemia or myelodysplastic syndromes need repeated blood transfusions and

consequently, long-term daily chelation therapy. Jadenu oral tablets can be taken in a single step, with or without a light meal, simplifying administration of treatment for chronic iron overload. Exjade is a dispersible tablet that must be mixed in liquid and taken on an empty stomach. Jadenu is approved under accelerated approval based on a reduction of liver iron concentrations and serum ferritin levels. Continued approval for this indication may be contingent upon verification and description of clinical benefit in confirmatory trials.

“Novartis has had a long-term commitment to improving the lives of patients with chronic iron overload,” said Bruno Strigini, President, Novartis Oncology. “Exjade transformed iron chelation therapy. We responded to feedback from patients and their physicians, and now Jadenu, by simplifying treatment administration, offers an important new option to help meet these patients’ needs.”

Chronic iron overload is a life-threatening cumulative toxicity that results from blood transfusions required to treat sickle cell disease, myelodysplastic syndromes, thalassemia and other conditions. Chronic iron overload also can

occur in patients with NTDT due to increased iron absorption in the stomach and intestines. If left untreated, chronic iron overload can damage the liver and heart.

Jadenu contains deferasirox, the same active ingredient that is in Exjade, a medicine that has been used by patients with chronic iron overload for almost 10 years. Exjade currently is the most-prescribed chelator in the United States.

“Jadenu is an exciting development for patients with chronic iron overload who have been eager for alternative treatment options,” said Dr. Elliott Vichinsky, Director of Hematology and Oncology at the University of California, San Francisco (UCSF) Benioff Children’s Hospital Oakland and Professor, UCSF School of Medicine. “Taking iron chelation therapy every day has sometimes been a challenge for them. The administration of Jadenu oral tablets once a day is simple.”

Novartis has submitted additional regulatory applications for Jadenu in other countries worldwide.

To view the complete press release go to <http://www.novartis.com/newsroom/media-releases/en/2015/1907710.shtml>.

Cord Blood Registry: Providing Cord Blood Banking to Families in Need

**Heather Harris, MS – CGC Director of
Clinical Operations at Cord Blood Registry**

Cord blood is a rich source of blood forming stem cells (called hematopoietic stem cells or HSCs). For more than 20 years, cord blood has been used as a source of stem cells for patients requiring a stem cell transplant as part of their treatment for bone marrow failure conditions, like the myelodysplastic syndromes (MDS), as well as other hematological diseases and malignancies. To date, more than 35,000 cord blood stem cell transplants have been performed worldwide. In transplant medicine, HSCs are used to regenerate the patient's blood and immune systems after chemotherapy and/or radiation treatments have been given to suppress or ablate the patient's own blood and immune systems.

Cord blood HSCs have advantages over other sources of HSCs, such as those derived from bone marrow, including a lower risk of graft-vs-host disease, which can be a serious side effect of HSC transplants. Depending on the condition being treated, the stem cells

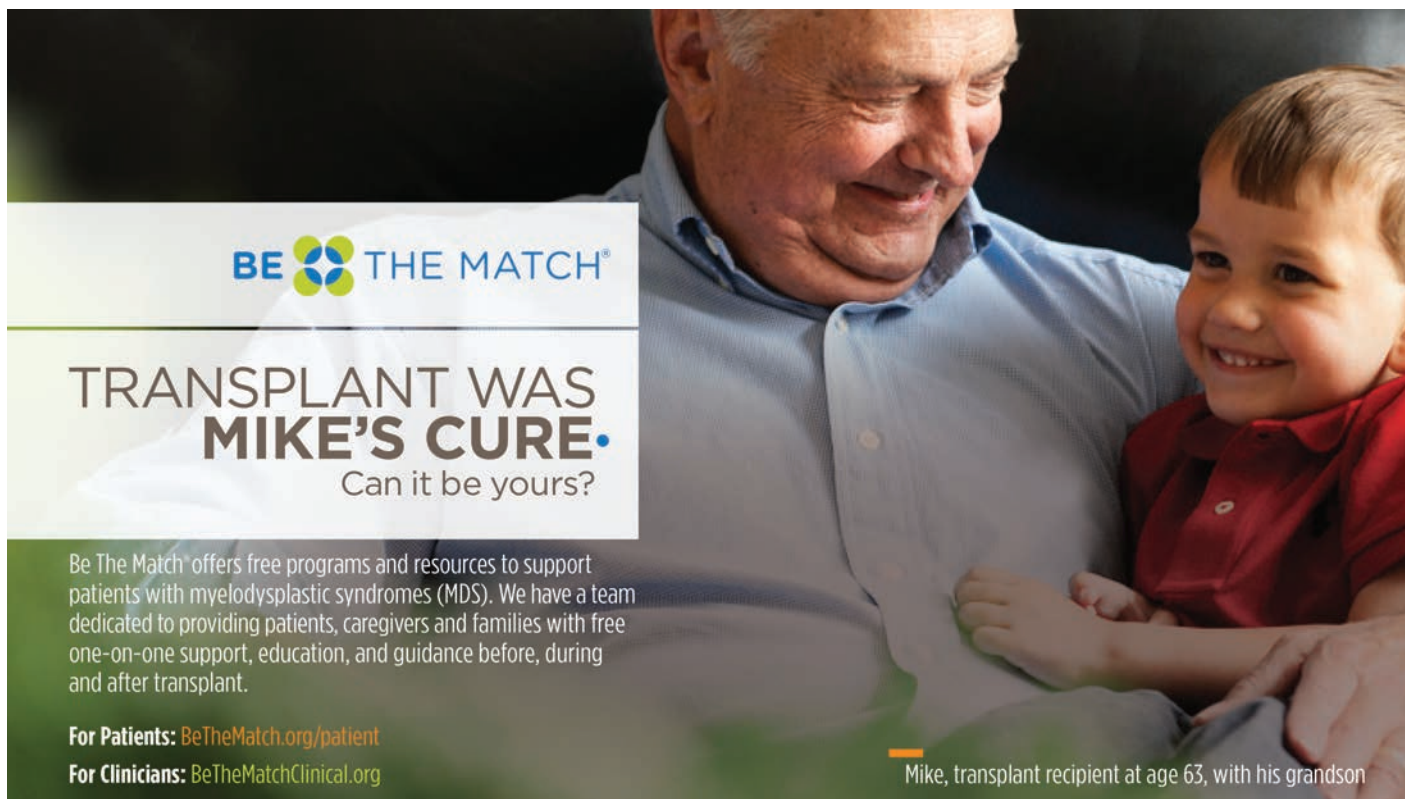
used in a transplant may come from a healthy donor or from the patient themselves. In treating patients with MDS, the stem cells typically come from a healthy donor, preferably a sibling who is a good genetic match to the patient. Using stem cells from a closely matched relative helps to improve transplant outcomes.

Cord blood stem cells can be collected and stored at the time of birth and either donated to a public cord blood bank for use by an anonymous patient in need or stored in a private bank for potential use within the family. Cord Blood Registry® (CBR®) is the largest and most experienced family cord blood bank. We offer cord blood collection, processing and storage services to families who wish to save their children's cord blood at the time of birth for the family's potential use in the future. By saving cord blood at the time of birth, families can ensure that they have access to this important resource should anyone in the immediate family ever require a HSC transplant. Many patients with hematological conditions, including MDS, have no family history of the condition, and therefore banking at the time of birth provides a "safety-net" for families. In fact, current estimates suggest that, over an

individual's lifetime, the odds of requiring an HSC transplant are 1 in 217. When stored under the proper conditions, cord blood stem cells are expected to last indefinitely, providing a long-term resource for families' potential use.

As part of CBR's commitment to families in need, our Newborn Possibilities Program® offers cord blood processing and storage at no cost for families in which a parent or full sibling of the newborn is diagnosed with a condition for which HSC transplant may be a treatment option. This program provides families with access to a potential source of valuable stem cells, should a transplant be required. To date, CBR has enrolled more than 5,000 families into the Newborn Possibilities Program. Though MDS is typically diagnosed in individuals past child bearing age, families with MDS are eligible to apply for the program. In addition, CBR has Genetic Counselors on staff to help families make informed choices about their newborn stem cell banking options and to answer questions regarding medical indications for cord blood banking.

For more information about Cord Blood Registry or the Newborn Possibilities Program please call us at 1-888-cordblood or visit www.cordblood.com.



BE THE MATCH®

**TRANSPLANT WAS
MIKE'S CURE.**
Can it be yours?

Be The Match® offers free programs and resources to support patients with myelodysplastic syndromes (MDS). We have a team dedicated to providing patients, caregivers and families with free one-on-one support, education, and guidance before, during and after transplant.

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

Mike, transplant recipient at age 63, with his grandson

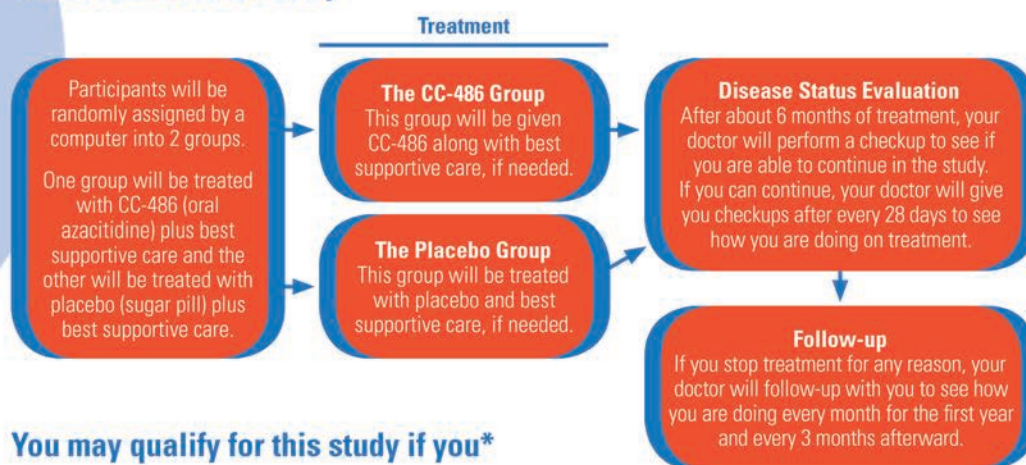


Do you have myelodysplastic syndromes (MDS)? You may be eligible for this clinical study

Announcing the QUAZAR Lower-Risk MDS Study

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

The QUAZAR MDS Study



You may qualify for this study if you*

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

You may not be eligible for this study if you*

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

* Additional criteria apply.

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

For more information about this study

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



© 2014 Celgene Corporation 8/14 QUAZAR® is a registered trademark of Celgene Corporation.

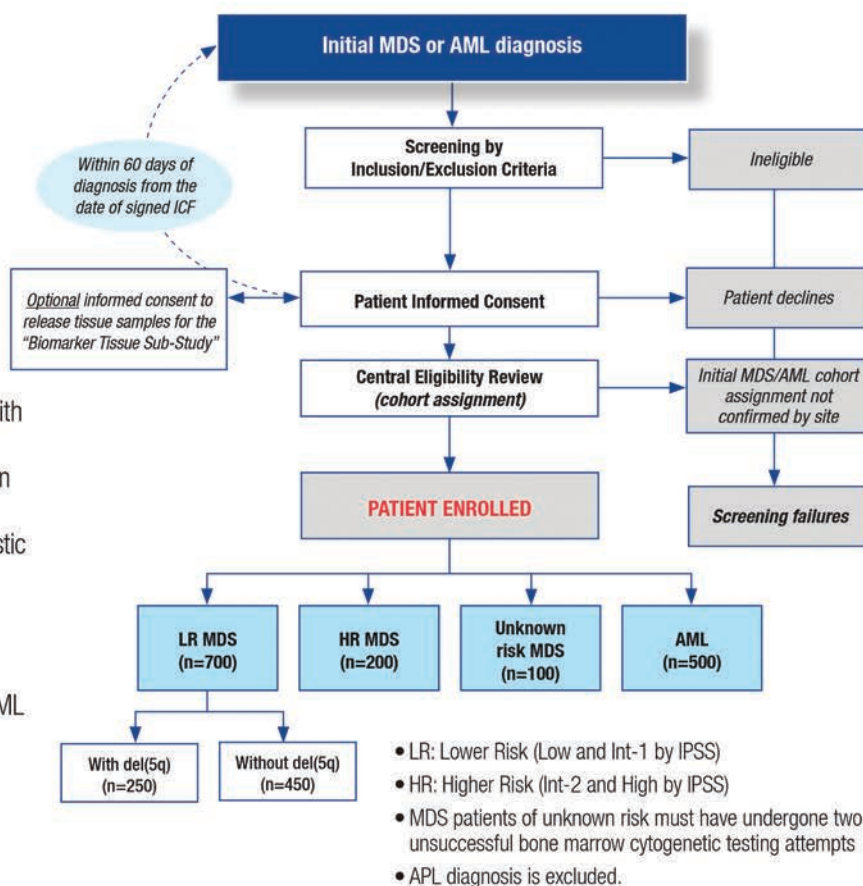
Celgene is researching the following objectives in MDS and AML patient populations:

- 🔴 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

- 🔴 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

Note: Concomitant patient enrollment in other studies is permitted.

- Your site supports clinical trials
- Your site sees at least 2 suspected MDS or AML patients per quarter



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





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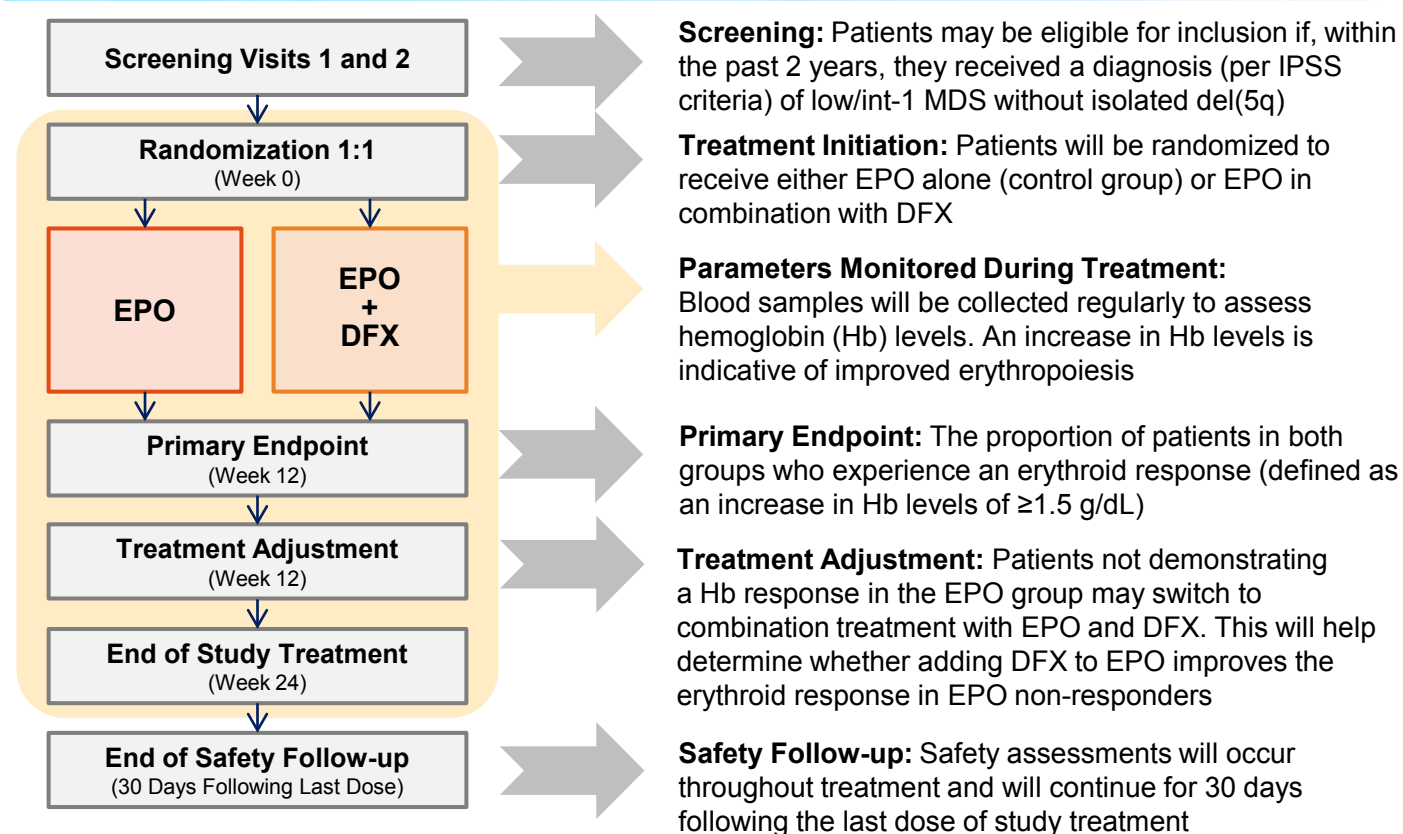
Overview

KALLISTO is an open-label, Phase II, pilot study of deferasirox (DFX) and erythropoietin (EPO) versus EPO alone in patients with lower-risk myelodysplastic syndromes (MDS).

EPO is a hormone that stimulates red blood cell production (erythropoiesis) in the bone marrow. Treatment with EPO can increase healthy blood cell counts in patients with MDS. DFX – an orally-administered iron chelator – may act synergistically with EPO to increase the production of healthy red blood cells.

The objective of KALLISTO is to test whether this potential synergy of DFX and EPO (versus EPO alone) improves erythropoiesis in patients with lower-risk MDS (low/int-1 per International Prognostic Scoring System [IPSS] criteria).

Study Schedule



To learn more about KALLISTO, call Novartis Pharmaceuticals (1-888-669-6682) or contact your local Novartis Medical Science Liaison (ClinicalTrials.gov Identifier: NCT01868477)



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

ANNOUNCING A CLINICAL RESEARCH TRIAL

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

ABOUT THE STUDY

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

ELIGIBILITY

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

CRITERIA

Inclusion Criteria:

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

Exclusion Criteria:

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

Clinicaltrials.gov Identifier #: ASTX727-01

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



BLAST MDS Trial

Birinapant pLus Azacitidine Study in the Treatment of MDS

Clinical Research Trial of Azacitidine With/Without Investigational Agent Birinapant in MDS/CMML Now Open for Accrual

STUDY TL32711-0094:

A Phase 2, Randomized, Double-Blind, Placebo-Controlled Study of Azacitidine With or Without Birinapant With a Single Arm Open-Label Run-In Phase in Subjects With Higher Risk Myelodysplastic Syndrome or Chronic Myelomonocytic Leukemia

Key Inclusion Criteria:

- Adults with morphologically confirmed diagnosis of intermediate, high or very high risk MDS/Secondary MDS/CMML based on FAB or WHO classification, IPSS-R score >3
- Previously untreated with hypomethylating agents for MDS or CMML, ECOG of 0 or 1
- Adequate renal and liver function
- Female of child bearing potential must not be pregnant and willing to use effective birth control methods for the duration of study and 3 months thereafter.

Key Exclusion Criteria:

- Relapsed or refractory MDS or AML (except for RAEB-t patients who are not candidates for intensive AML treatment)
- Participated in any interventional study within 4 weeks of randomization or 5 half-lives, whichever is longer or received any hematopoietic growth factors for within 14 days prior to screening.
- Prior malignancy or secondary malignancy within the prior 2 years (except in situ cervical cancer, squamous cell carcinoma or basal cell carcinoma of the skin).
- Planned hematopoietic stem-cell transplant.
- Known diagnosis of human immunodeficiency virus or chronic active Hepatitis B or C.
- Uncontrolled hypertension or history of cranial nerve palsy
- Impaired cardiac function, uncontrolled cardiac arrhythmias despite medications.

Primary Objective: Overall response rate comparison between azacitidine plus birinapant versus azacitidine plus placebo.

Secondary Objective: Compare hematological improvement, transfusion requirements, safety, and time to respond, duration of response, relapse free survival and overall survival.

For additional information on the BLAST study, please visit:
www.clintrials.gov clinicaltrials.gov identifier: NCT02147873



KaloBios Pharmaceuticals, Inc. is now recruiting the Phase 2 portion of their trial of KB004 in MDS and MF patients. The study consists of IV infusion once weekly for a 21 day dosing cycle with KB004 250 mg (the recommended Phase 2 dose). This portion of the study will be to further study the activity of KB004 and explore the safety of KB004. The ClinicalTrials.gov Identifier is NCT01211691.

TO BE ELIGIBLE FOR THE STUDY PATIENTS WILL HAVE:

- ✓ Confirmed MF or MDS with an acceptable level of EphA3 expression
- ✓ Confirmed hematologic malignancy refractory to or progressed following standard treatments, or subjects not considered medically suitable to receive standard of care treatment or who refuse standard of care treatment
- ✓ Acceptable level of EphA3 expression
- ✓ Eastern Cooperative Oncology Group (ECOG) ≤ 1
- ✓ Acceptable laboratory results

PATIENTS ARE NOT ELIGIBLE FOR THE STUDY IF THEY HAVE THE FOLLOWING:

- ✗ History of or current central nervous system (CNS) involvement that may increase risk of bleeding
- ✗ Recent major surgery
- ✗ Ongoing surgical or wound healing complications
- ✗ Active clinically significant bleeding
- ✗ Uncontrolled hypertension
- ✗ Significant intercurrent illness
- ✗ Known history of prolonged bleeding times or platelet dysfunction
- ✗ Active infection requiring IV antibiotics, IV antifungals, or IV antivirals within 2 weeks prior to Cycle 1, Day 1

Study centers are now recruiting in the United States including California (Palo Alto and Sacramento), Florida (Miami and Tampa), Ohio (Cleveland), and Texas (Houston). In Australia centers are recruiting in Westmead, New South Wales; Adelaide, South Australia; Prahran, Victoria; and Queensland, Australia.

For questions, feel free to contact: Kate Doherty at Kdoherty@kalobios.com / 1-650-243-3126.

VISIT US ONLINE

Visit us at www.mds-foundation.org



MDS FOUNDATION HEADQUARTERS

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800-MDS-0839 (*within US*)
609-298-1035 (*outside US*)
609-298-0590 (*fax*)

Or Write:

The MDS Foundation, Inc.
4573 South Broad Street
Suite 150
Yardville, NJ 08620

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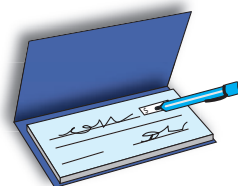


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