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MDS News

The Newsletter of The Myelodysplastic Syndromes Foundation, Inc.

MDS NEWS HIGHLIGHTS

FROM THE GUEST EDITOR'S DESK

- **REAL WORLD RESULTS OF CLINICAL TRIALS IN PATIENTS WITH LOWER-RISK MDS**

Presented by: *Theo de Witte, MD, PhD*
Radboud University Medical Center
Radboud Institute of Molecular Life Sciences, Nijmegen, The Netherlands

PLAN TO ATTEND

17TH INTERNATIONAL CONGRESS ON MYELODYSPLASTIC SYNDROMES

3–6 May 2023
Marseille, France

ASH 2023: MDS FOUNDATION BREAKFAST SYMPOSIUM

December 8, 2023, San Diego, California

IN THIS ISSUE

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GUEST EDITORIAL

REAL WORLD RESULTS OF CLINICAL TRIALS IN PATIENTS WITH LOWER-RISK MDS

THEO DE WITTE, MD, PHD
on behalf of the European MDS Registry (EUMDS) participants
Radboud University Medical Center, Radboud Institute of Molecular Life Sciences
Nijmegen, The Netherlands

INTRODUCTION

MDS, particularly lower-risk MDS (LR-MDS), suffers from a profound lack of prospective randomized interventional data obtained in clinical trials, mainly because of the advanced age and the frequent co-morbidities leading to a poor physical and restricted Health-Related-Quality of Life. Prospective collection of longitudinal observational data linked with translational studies in non-selected real-world populations may be the solution to this lack of prospective randomized clinical trials.

For this reason, the MDS working research group within the European LeukemiaNet started in April 2008 a prospective observational study in patients with recently diagnosed LR-MDS from 11 European countries. The EUMDS Registry extended gradually to 19 European countries and to all subtypes of MDS, including higher-risk MDS and chronic myelomonocytic leukemia (CMML). Currently, >3100 patients from >400 sites have been registered and >40 studies, including studies on patient-reported outcomes, time-dependent variables, including red blood cell transfusion (RBCT) dependency and iron toxicity parameters, such as hepcidin levels and labile plasma variables, have been summarized in our recent perspective overview.[1]

Most studies have been restricted to patients with LR-MDS (87%), because data on the other groups are heterogeneous and more recently obtained. We showed recently in a large study on 1276 patients that even a very low RBCT density, defined as 0.1 to <0.5units/month, was associated with a significantly inferior progression-free survival (PFS), especially after adjustment for the impact of administered interventions with lenalidomide, Erythropoiesis-Stimulating Agents (ESAs) or iron chelation therapy.[2]

In addition, we analyzed in a recent study on almost 2,400 patients with LR-MDS, the impact of competing causes of death on outcome of various groups of patients with MDS using relative survival studies.[3] Relative survival estimates the ratio of the observed cumulative probability of survival in the EUMDS subjects and the survival that would have been expected if the group had only been subject to the background mortality in the general population of their country adjusted for sex and age. The difference between the 2 curves describes the impact of non-related death within the study population. The impact of non-related causes of death on overall survival and the calculated relative survival of the overall study population increases over time from around 10% at 3 years after diagnosis to 20% at 6 years. Increasing age has a considerable impact on the contribution of non-related causes of death. As expected, patients older than 80 years die more frequently (25%) from non-related causes after 5 years observation than patients younger than 70 years: only 5%.

Very-low risk patients die more frequently from competing causes of death, as indicated by a 12% higher relative survival at 3 years observation, compared to only 3% higher relative survival in the high-risk groups. This indicates that non-competing causes of death are playing a higher role when assessing the impact of interventions on gained numbers of years in lower-risk and older, non-fitter patients.

Very-low risk, low-risk elderly patients are usually excluded from regular randomized interventional studies and only a few drugs have been explored in prospective randomized clinical trials. Up till now, ESAs, lenalidomide, iron chelators and recently luspatercept have been investigated by standard prospective studies.

Reimbursement of ESAs for treatment of anemia varies from country to country in Europe depending on transfusion-status and approval by national health authorities, but also local routines play a role. We assessed in an earlier study the outcomes of 897 patients, 484 ESA treated and 413 untreated with ESA. ESA treatment was associated with a nonsignificant survival benefit (HR 0.82, 95% CI: 0.65–1.04, P=0.09). This benefit was larger amongst patients without prior transfusions (P=0.07). We concluded that appropriate use of ESAs may delay the onset of a regular transfusion need in patients with lower-risk MDS.[4]

Therefore, we analyzed subsequently in a time-dependent interactive, observational study the impact of RBCT dependency on the outcome of ESA treatment. We divided the transitions of the study group of 1,168 patients in 4 subgroups over time at 6 months intervals: 1. Patients who did not receive RBCT nor ESA; 2. patients who received RBCT before start of ESA; 3. patients who received ESA after start of RBCT; 4. patients who received RBCT only. This analysis clearly showed the ESA treatment impact on RBCT dependency, HRQoL and PFS was more pronounced when ESA treatment was initiated before introduction of regular RBCT. A low and high transfusion intensity at the starting point of ESA treatment did not influence the outcome significantly. The regular prospective interventional ESA studies define RBCT dependency at much higher levels as defined in the EUMDS studies, which will result in an underestimated prognostic outcome in the control groups and an underestimated impact in the interventional arm. The preliminary data of this study has been presented during the annual EHA meeting in 2022.

The EUMDS registry conducted a study on 490 nonchelated and 199 chelated patients using iron chelation therapy as a time-dependent variable.[5] The propensity-score analysis matching for all relevant variables, and a multivariate Cox proportional hazard model restricted to the deferasirox treated patients resulted in the adjusted HR for OS of 0.34 (95% CI: 0.22-0.53). An erythroid response occurred in 77 chelated patients: 61 patients had a reduction in transfusion density, and 16 patients who did not have a reduction in transfusion density became transfusion independent during at least one visit interval. Currently, this data are compared with the outcome of the Telesto trial, the only prospective, randomized, placebo-controlled study of ICT in MDS patients, comparing deferasirox with a placebo-control group.[6]

Our data indicates that the classical interventional clinical trials should be confirmed by observational studies in less selected, real-world populations. Unfortunately, funding of the observational studies, is less incorporated in the research programs of pharmaceutical companies.

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DID YOU KNOW?

The Myelodysplastic Syndromes (MDS) Foundation, Inc. was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS.

Until the Foundation was set up, no formal working group had been devoted to MDS. Since its inception, we have conducted 16 international symposia in Austria, England, the United States (Chicago, Washington, DC), Spain (Barcelona, Valencia), Czech Republic, Sweden, France, Japan, Italy, Greece, Scotland, Germany, Denmark, and Canada. The 17th International Congress will be held in Marseille, France on May 3-6, 2023. We are also looking forward to our 3rd Regional Symposium on MDS 15-16 March 2024 in Kyoto, Japan. Our prior Regional Symposia were held in São Paulo, Brazil and Tel-Aviv, Israel.

A major MDS Foundation effort is our international information network. This network provides patients with referrals to Centers of Excellence, contact names for available clinical trials, sharing of new research and treatment options between physicians, and extension of educational support to physicians, nurses, pharmacists and patients.

In response to the needs expressed by patients, families, and healthcare professionals, we have established patient advocacy groups, research funding, and professional educational initiatives.

The MDS Foundation is a publicly supported organization, exempt from federal income tax under section 501(C)(3) of the IRS code.

Learn more about
The Myelodysplastic Syndromes Foundation, Inc.
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MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

MEETING HIGHLIGHTS AND ANNOUNCEMENTS

ON BEHALF OF THE MDS FOUNDATION AND OUR BOARD OF DIRECTORS, THANK YOU FOR JOINING OUR BREAKFAST SATELLITE SYMPOSIUM!

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The Myelodysplastic Syndromes Foundation, Inc.

Advancing Research & Patient Care

THE 17TH INTERNATIONAL CONGRESS ON MYELODYSPLASTIC SYNDROMES

Marseille, France | 3-6 May 2023

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INTERNATIONAL WORKING GROUP

MDS FOUNDATION INTERNATIONAL WORKING GROUP FOR PROGNOSIS IN MDS

LATEST NEWS REGARDING PROJECTS OF THE INTERNATIONAL WORKING GROUP FOR PROGNOSIS IN MDS (IWG-PM)

At the 2022 American Society of Hematology meeting the members of the International Working Group for Prognosis in MDS (IWG-PM) held a virtual group meeting, coordinated by Peter Greenberg. Elsa Bernard presented an update of the data generated to produce the **clinical-molecular MDS prognostic risk model (IPSS Molecular or IPSS-M)**,[1] with major effort by the lab of Elli Papaemmanuil at Memorial Sloan-Kettering Cancer Center, under the aegis of the MDS Foundation. To this end, mutations in diagnostic MDS samples from 2957 patients from 13 countries and 25 global centers were analyzed. Clinical, cytogenetic, and molecular variables were evaluated for associations with leukemic transformation and overall survival. At least one genetic driver alteration was found in 94% of patients. Multivariate analysis identified multihit *TP53*, *FLT3* mutation, and *MLL* partial tandem duplication as top genetic predictors of adverse outcomes. *SF3B1* mutation was associated with favorable outcomes, but this was modulated by co-mutation patterns. Using hematologic, cytogenetic and molecular data on 31 genes, the IPSS-M was developed as a continuous score. A discrete six-category risk schema was further derived. The IPSS-M re-stratified 46% of MDS patients compared to the IPSS-R, improving discrimination across clinical endpoints. A web calculator was built that, upon entering predictor variables, outputs a patient-tailored score, its corresponding risk category, and temporal estimates for clinical endpoints. The IPSS-M prognostic risk score is personalized, interpretable and reproducible. Combining conventional parameters with genomic profiling, the IPSS-M represents a valuable tool for clinical decision-making for MDS patients. An app is available to supplement the weblink now in general use for calculating the IPSS-M (see page 8).

PETER L. GREENBERG, MD
Professor of Medicine/Hematology
Stanford University School of Medicine

IWG-PM
INTERNATIONAL WORKING GROUP FOR THE PROGNOSIS OF MDS

THE IWG-PM/MOLECULAR GROUP PROJECT IS ONGOING WITH ACTIVE PLANS FOR FURTHER DEVELOPMENT OF A GLOBAL CLASSIFICATION AND PROGNOSTIC SCHEMA FOR MDS.

Other ongoing aims for the IWG's Molecular Project, reviewed by Elsa Bernard at the meeting included current efforts generating data for an **MDS Classification model**. This will be further discussed at the upcoming International MDS Symposium in Marseille.[2] Elsa also described her ongoing efforts for further evaluating the molecular features of **treatment-related MDS** (tMDS).

Supplementing this project, Maritxell Nomdedeu presented an update of her work in association with Andrea Kuendgen, Heinz Tuechler and others of the IWG regarding **cytogenetic abnormalities** from a large cohort of IWG tMDS patients compared to those from primary MDS.[3]

Maria Sirenko, from MSK lab of Elli Papaemmanuil, presented an update of the molecular and clinical features of patients from the IWG database with ***UBA1* mutations and VEXAS syndrome**.[4]

One of the recent recipients of the MDS Foundation's Young Investigators Award, Syed Mian, from the UK Crick Institute Lab of Dominique Bonnet, presented an update of their data regarding a 'Novel scaffold xenograft model for evaluation of mesenchymal stem cell/HPC interactions'.[5]

Future plans are to enhance collaborative interactions with the IWG group investigators for the above ongoing projects.

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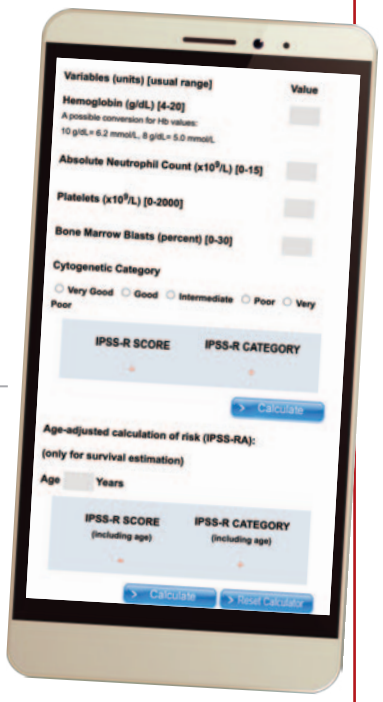
This global project is being coordinated by Ben Ebert and Peter Greenberg (co-Chairs), Rafael Bejar and Ellie Papaemmanuil, with statistical support by Donna Neuberg, Kristin Stevenson and Heinz Tuechler.

MDS RISK ASSESSMENT CALCULATORS

THE IWG-PM UNDER THE AEGIS OF THE MDS FOUNDATION, INC. HAS DEVELOPED TWO PROGNOSTIC TOOLS, THE IPSS-M AND IPSS-R CALCULATORS, TO DETERMINE A PATIENT'S RISK OF PROGRESSING TO ACUTE MYELOID LEUKEMIA (AML).



NEW IPSS-M CALCULATOR

The IPSS-M is the newest MDS prognosis calculator that combines genomic profiling with hematologic and cytogenetic parameters, improving the risk stratification of patients with MDS. This is a valuable tool for clinical decision-making, offering the prospect of tailoring diagnosis and therapeutic interventions to each patient's molecular profile.

https://www.mds-foundation.org/mds-iwg-pm/

DOWNLOAD IPSS-M CALCULATOR APP

https://apps.apple.com/gb/app/ipss-m-risk-calculator/id6447183381

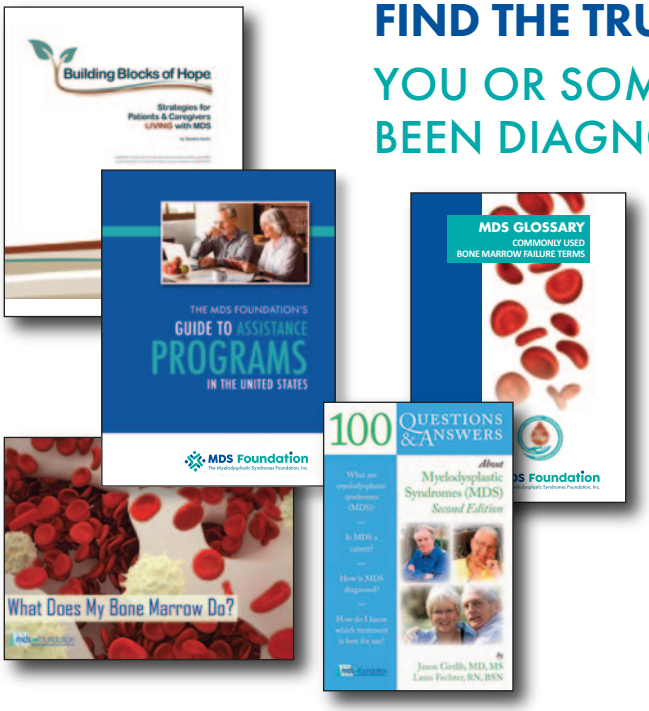
IPSS-R CALCULATOR

The IPSS-R is the current MDS prognosis calculator that combines hematologic and cytogenetic parameters to determine an MDS patient's risk stratification. This calculator tool includes clinical features of marrow blasts, cytogenetics, depth of cytopenias and age as well as the additive differentiate features for patient survival of performance status, serum ferritin, LDH, beta-2 micro globulin and marrow fibrosis.

https://www.mds-foundation.org/advanced-calculator

DOWNLOAD IPSS-R CALCULATOR APP

https://play.google.com/store/apps/details?id=com.mdsfoundation.ipssm



FIND THE TRUSTED RESOURCES YOU NEED...

YOU OR SOMEONE YOU KNOW HAS BEEN DIAGNOSED WITH MDS

Hearing the words Myelodysplastic Syndromes or MDS can be frightening. The diagnosis of MDS is often unexpected and filled with both immediate and long-term challenges. You probably have many questions. Have you accessed your complete set of tools to prepare, participate, and LIVE with MDS?

Dealing with MDS can be very difficult, but it helps to have resources that are reliable and easy to understand.

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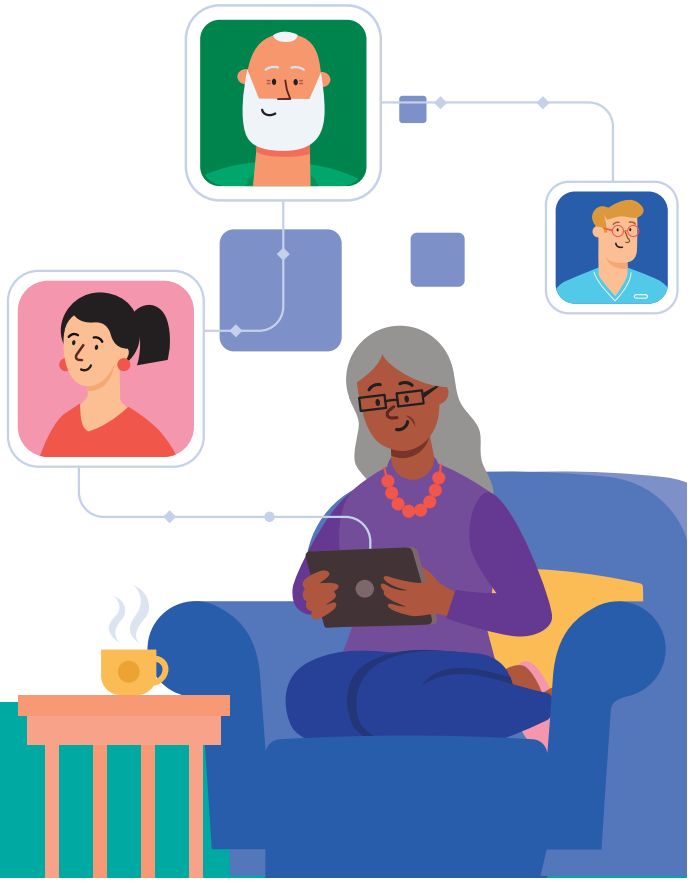
- How has MDS affected your other medical conditions?
- What do you wish you were told at the point of your diagnosis that you know now?

How sharing your stories can help others?

Your experiences will help the MDS Foundation uncover the true unmet needs associated with your condition, informing future patient support programs and research.



Join the MDS community today!

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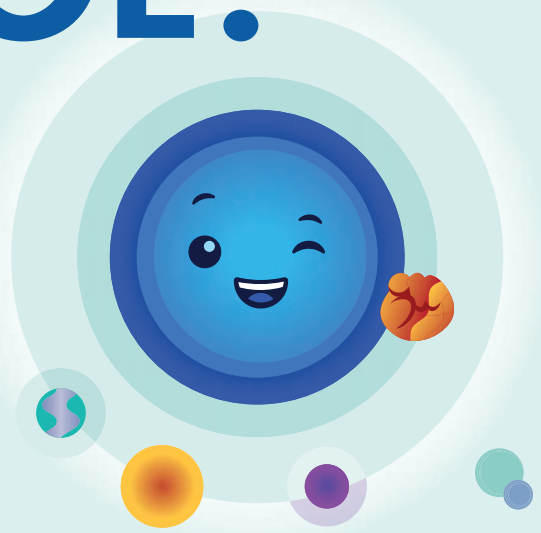
COLLOQUY

MEET JOE!

Representing a nucleus, **JOE** collates information and resources together in one place. JOE invites patients, caregivers, and loved ones to embark on a Journey Of Empowerment, **allowing them to be their own best advocates**.



Module 1
The essential facts of MDS

Module 2
Understanding the impact of MDS on your body

Module 3
Understanding your MDS diagnosis

Module 4
Managing the signs and symptoms of MDS

Module 5
Treatment of MDS

Module 6
Patient empowerment

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QUESTIONS ANSWERED

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DO YOU KNOW YOUR MDS SUBTYPE, IPSS-R SCORE & GENE MUTATION PROFILE?

MDS treatment is individualized based on a patient's subtype, IPSS-R score and, to some extent, genetic mutation. This knowledge will empower patients and their caregivers to take a more active role in decisions about their treatment and advocate for appropriate treatments that may prolong their life and improve their quality of life. The following information is designed to help you understand how your subtype and IPSS-R score are determined, as well as general information on genetic mutations commonly found in MDS and the importance of genetic testing for these mutations.

Knowing your subtype, IPSS-R score and gene mutation profile will help facilitate discussions with your healthcare provider on what this means for you personally and help select the best treatment options.

IPSS-R SCORE

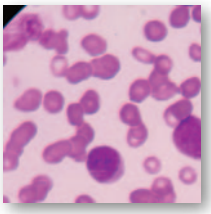
The IPSS-R is a classification system used by doctors to help predict a person's risk of developing AML and overall survival without treatment.

MDS SUBTYPE

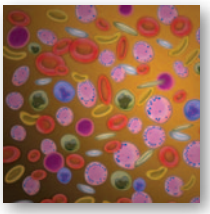
MDS is classified into several different subtypes based on the following features: Blood cell counts, Percentage of blasts in the bone marrow, and Cytogenetics.

MUTATION PROFILE

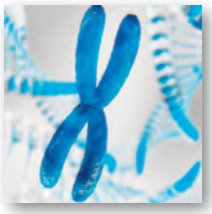
Genetic mutations occur when a gene is damaged and alters the genetic message. Mutations can potentially identify effective therapies to treat your disease.



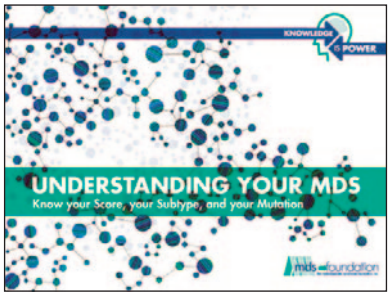
BONE MARROW BLAST



MDS-RS-MLD



CYTOGENETICS



UNDERSTANDING YOUR MDS: KNOW YOUR SCORE, YOUR SUBTYPE, AND YOUR MUTATION

This brochure is intended to help you better understand the diagnosis of MDS. Created by the MDS Foundation staff, Board of Directors, and medical and scientific leaders, it will explain the various MDS subtypes; how a prognostic scoring system is designed and where you can place yourself with the help of your physician and other health professionals. You will learn about normal and abnormal blood cells; leukemic blasts; blood counts; chromosomes and molecular mutations that may assist your provider in further modifying your subtype and, possibly, selecting the type of therapy for you.

John M. Bennett, MD
First Chair and Founding Member of the MDS Foundation

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- In addition, along with your $500 CoE renewal payment, your annual MDSF Professional Membership dues are waived. MDSF Professional Members are also listed, by name, on our website and in our printed newsletters.
- The work of your institution can be shared with our patient and professional contacts via our website and/or our social media channels. We can spread the word of your clinical trials, research projects, etc.

Would you like your treatment center to become part of the referral system for MDS patients and be designated as a Center of Excellence?

To be recognized as a Center of Excellence, an institution must have the following:

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

Please contact the Foundation for further information and an application form for your center. *The following centers have qualified as MDS Centers of Excellence:*

UNITED STATES

ALABAMA

University of Alabama at Birmingham
Birmingham Comprehensive Cancer Center
Birmingham, Alabama
Kimo Bachiashvili, MD

ARIZONA

Mayo Clinic Hospital
Phoenix, Arizona
Cecilia Arana Yi, MD

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

CALIFORNIA

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

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

Moores Cancer Center–UC San Diego Health
San Diego, California
Rafael Bejar, MD, PhD/Tiffany N. Tanaka, MD

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

UCLA Health Hematologic Malignancies and Stem Cell Transplant Program
Los Angeles, California
Gary J. Schiller, MD

University of Southern California
Keck School of Medicine
Los Angeles, California
Casey L. O'Connell, MD

COLORADO

University of Colorado School of Medicine
University of Colorado Cancer Center
Aurora, Colorado
Daniel Aaron Pollyea, MD, MS
Maria Amaya, MD, PhD – Practice Location: Rocky Mountain Regional VA
Christine McMahon, MD – Practice Location: UCHealth Blood Disorders and Cell Therapies Center – Anschutz Medical Campus

CONNECTICUT

Yale Cancer Center/Smilow Cancer Hospital
Yale University School of Medicine
New Haven, Connecticut
Amer Zeidan, MD

FLORIDA

Blood and Marrow Transplant Center
AdventHealth Cancer Institute
Orlando, Florida
Juan Carlos Varela, MD, PhD

Mayo Clinic
Jacksonville, Florida
James M. Foran, MD

Moffitt Cancer Center
Tampa, Florida
Rami Komrokji, MD
Alison R. Walker, MD

Sylvester Comprehensive Cancer Center
University of Miami, Miller School of Medicine
Miami, Florida
Stephen D. Nimer, MD/Mikkael Sekeres, MD, MS

University of Florida Shands Hospital
Gainesville, Florida
Zeina Al-Mansour, MD

GEORGIA

Emory Winship Cancer Institute
Emory University School of Medicine
Atlanta, Georgia
Amelia Langston, MD
Nikolaos Papadantonakis, MD, PhD, MSc

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

ILLINOIS

Loyola University Chicago
Cardinal Bernardin Cancer Center
Maywood, Illinois
Stephanie B. Tsai, MD

Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Feinberg School of Medicine
Chicago, Illinois
Jamile Shammo, MD

Rush University Medical Center
Chicago, Illinois
Melissa L. Larson, MD

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

INDIANA

Indiana University Simon Cancer Center
Indianapolis, Indiana
Larry Cripe, MD/Hamid Sayar, MD, MS

IOWA

The University of Iowa Hospitals and Clinics, Holden Cancer Center
Iowa City, Iowa
Grerk Sutamtewagul, MD

KANSAS

The University of Kansas Cancer Center
Westwood, Kansas
Barry Skikne, MD

MARYLAND

Johns Hopkins University School of Medicine
Baltimore, Maryland
Amy Elizabeth DeZern, MD

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

MASSACHUSETTS

Dana-Farber/Boston Children's Cancer and Blood Disorders Center
Boston, Massachusetts
Akiko Shimamura, MD, PhD

Dana-Farber Cancer Institute
Boston, Massachusetts
Richard M. Stone, MD
Benjamin Ebert, MD, PhD

Massachusetts General Hospital Cancer Center
Boston, Massachusetts
Timothy Graubert, MD

Tufts Medical Center
Boston, Massachusetts
Andreas Klein, MD

MICHIGAN

Barbara Ann Karmanos Cancer Institute Wayne State University
Detroit, Michigan
Jay Yang, MD

William Beaumont Hospital Cancer Center
Royal Oak, Michigan
Ishmael Jaiyesimi, DO

MINNESOTA

Mayo Clinic
Rochester, Minnesota
Aref Al-Kali, MD/Mark R. Litzow, MD/
Mrinal S. Patnaik, MBBS

University of Minnesota Medical Center, Fairview University of Minnesota Medical School
Minneapolis, Minnesota
Mark B. Juckett, MD

MISSOURI

Washington University School of Medicine Siteman Cancer Center
St. Louis, Missouri
John F. DiPersio, MD, PhD

NEBRASKA

University of Nebraska Medical Center
Omaha, Nebraska
Lori Maness, MD

NEW HAMPSHIRE

Dartmouth-Hitchcock Medical Center and Norris Cotton Cancer Center
Lebanon, New Hampshire
Kenneth R. Meehan, MD

NEW JERSEY

John Theurer Cancer Center at Hackensack University Medical Center
Hackensack, New Jersey
James McCloskey, MD

Rutgers Cancer Institute of New Jersey Rutgers University Hematologic Malignancies and Stem Cell Transplant
New Brunswick, New Jersey
Dale G. Schaar, MD, PhD

NEW MEXICO

University of New Mexico Comprehensive Cancer Center
Albuquerque, New Mexico
Leslie Andritsos, MD/Ala Ebaid, MD

NEW YORK

Albert Einstein Cancer Center/Albert Einstein College of Medicine of Yeshiva University
Bronx, New York
Aditi Shastri, MD/Amit Verma, MD

Columbia University Medical Center
New York, New York
Azra Raza, MD

Memorial Sloan-Kettering Cancer Center
New York, New York
Aaron D. Goldberg, MD, PhD

Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, Monter Cancer Center
Lake Success, New York
Steven L. Allen, MD

Laura & Isaac Perlmutter Cancer Center at NYU Langone Health
New York, New York
Maher Abdul Hay, MD

Icahn School of Medicine at Mount Sinai
New York, New York
Lewis R. Silverman, MD

New York Medical College/Westchester Medical Center, Zalmen A. Arlin Cancer Center
Valhalla, New York
Karen Seiter, MD

Roswell Park Cancer Center
Buffalo, New York
Elizabeth Griffiths, MD/James E. Thompson, MD

University of Rochester Medical Center
Rochester, New York
Jane L. Liesveld, MD

Weill Medical College of Cornell University New York Presbyterian Hospital
New York, New York
Gail J. Roboz, MD

NORTH CAROLINA

Atrium Health Levine Cancer Center
Charlotte, North Carolina
Srinivasa R. Sanikommu, MD, FACP
Michael Grunwald, MD

Duke University Medical Center
Durham, North Carolina
Carlos M. deCastro, MD

UNC Lineberger Comprehensive Cancer Center
Chapel Hill, North Carolina
Brandi Reeves, MD

Novant Health Cancer Institute
Charlotte, North Carolina
Patricia Kropf, MD

Wake Forest University School of Medicine Comprehensive Cancer Center
Winston-Salem, North Carolina
Bayard L. Powell, MD

OHIO

Cleveland Clinic Foundation, Taussig Cancer Center
Cleveland, Ohio
Jaroslaw Maciejewski, MD, PhD

Hoxworth Blood Center, George L. Strike Bone Marrow Transplant Program University of Cincinnati – UC Health
Cincinnati, Ohio
Emily Curran, MD

The Ohio State Comprehensive Cancer Center, James Cancer Hospital and Solove Research Institute
Columbus, Ohio
James S. Blachly, MD/Uma M. Borate, MD

PENNSYLVANIA

Allegheny Health Network Cancer Institute Western Pennsylvania Hospital
Pittsburgh, Pennsylvania
Salman Fazal, MD

Fox Chase-Temple University Hospital Bone Marrow Transplant Program
Philadelphia, Pennsylvania
Henry Fung, MD, FACP, FRCPE/Rashmi Khanal, MD,
Michael Styler, MD/Asya Varshavsky-Yanovsky, MD, PhD

UPMC Cancer Center
Pittsburgh, Pennsylvania
Anastasios Raptis, MD/James M. Rossetti, DO

University of Pennsylvania Cancer Center
Philadelphia, Pennsylvania
Keith W. Pratz, MD

Sidney Kimmel Cancer Center at Thomas Jefferson University Hospital
Philadelphia, Pennsylvania
Lindsay Wilde, MD

TENNESSEE

Vanderbilt University Medical Center
Nashville, Tennessee
Sanjay Mohan, MD/Michael R. Savona, MD

TEXAS

Texas Oncology – San Antonio
San Antonio, Texas
Roger M. Lyons, MD, FACP/John S. Renshaw, MD

Texas Oncology – Austin Midtown
Austin, Texas
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University of Texas, MD Anderson Cancer Center
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Robert H. Collins, Jr., MD, FACP/Yazan Madanat, MD

UTAH

University of Utah Huntsman Cancer Institute
Salt Lake City, Utah
Afaf Osman, MD/Paul J. Shami, MD

VIRGINIA

University of Virginia
Charlottesville, Virginia
Michael Keng, MD

WASHINGTON

Fred Hutchinson Cancer Research Center
University of Washington
Seattle Cancer Care Alliance
Seattle, Washington
Joachim Deeg, MD/Bart L. Scott, MD

WASHINGTON, DC

Georgetown University Hospital
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OUTSIDE THE UNITED STATES

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ARMENIA

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AUSTRIA

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Manju Sengar, MD

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Dublin, Ireland
Helen Enright, MD

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Moshe Mittelman, MD

Chaim Sheba Medical Center
Tel Hashomer, Israel
Drorit Grizim Merkel, MD

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Florence, Italy
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Tomoya Maeda, MD, PhD

Tokyo Medical College
Tokyo, Japan
Kazuma Ohyashiki, MD, PhD

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y Nutrición Salvador Zubiran
American-British-Cowdray Cancer Center
Mexico City, Mexico
Alvaro Aguayo, MD

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Nijmegen, The Netherlands
Saskia M.C. Langemeijer, MD

Vrije Universiteit Medical Center
Amsterdam, The Netherlands
Arjan A. van de Loosdrecht, MD, PhD

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Bergen, Norway
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Aleksander Skotnicki, MD, PhD

Medical University of Warsaw
Warsaw, Poland
Krzysztof Madry, MD

PORTUGAL

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Lisbon, Portugal
Joao F. Lacerda, MD

SAUDI ARABIA

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Riyadh, Saudi Arabia
Amr Hanbali, MD

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

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Singapore General Hospital
Aloysius Ho, MD

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Groote Schuur Hospital
Cape Town, South Africa
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SOUTH KOREA

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The Catholic University of Korea
Seoul, Korea
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Seoul National University Hospital
Seoul National University College of Medicine
Seoul, Korea
Dong Soon Lee, MD, PhD

Yonsei Cancer Centre, Severance Hospital
Yonsei University College of Medicine
Seoul, Korea
June-Won Cheong, MD, PhD

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Valencia, Spain
Guillermo F. Sanz, MD, PhD

Vall d'Hebron Institute of Oncology Universitary
Hospital Vall d´Hebron
Barcelona, Spain
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Karolinska University Hospital Huddinge
Stockholm, Sweden
Eva Hellström-Lindberg, MD, PhD

SWITZERLAND

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Basel, Switzerland
Jakob R. Passweg, MD, MS

Bern University Hospital and University of Bern
Bern, Switzerland
Nicolas Bonadies, MD

St. Claraspital AG
Basel, Switzerland
Stefani Parmentier, MD

University Hospital Zurich
Zurich, Switzerland
Markus G. Manz, MD/Stefan Balabanov, MD

TAIWAN

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Chang Gung University
Taoyuan, Taiwan
Lee-Yung Shih, MD

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

THAILAND

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

TUNISIA

Hospital Aziza Othmana
Tunis, Tunisia
Balkis Meddeb, MD

TURKEY

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

UKRAINE

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

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

Cambridge University Hospitals
Cambridge, United Kingdom
Alan J. Warren, MD, PhD

Christie NHS Foundation Trust
Manchester, United Kingdom
Mike Dennis, MD/Dan Wiseman, MD

King's College London &
King's College Hospital
London, United Kingdom
Ghulam J. Mufti, DM, FRCP, FRCPath

Queen Elizabeth Hospital
University Hospital Birmingham NHS Trust
Birmingham, United Kingdom
Manoj Raghavan, MD

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

St. James's University Hospital
St. James's Institute of Oncology
Leeds, United Kingdom
Catherine Cargo, MD

University Hospital Southampton
(NHS Foundation Trust)
Southampton, Hampshire, UK
Christopher Dalley, MD
Srinivasan Narayanan, MD

University Hospital of Wales
Cardiff, Wales
Jonathan Kell, MD

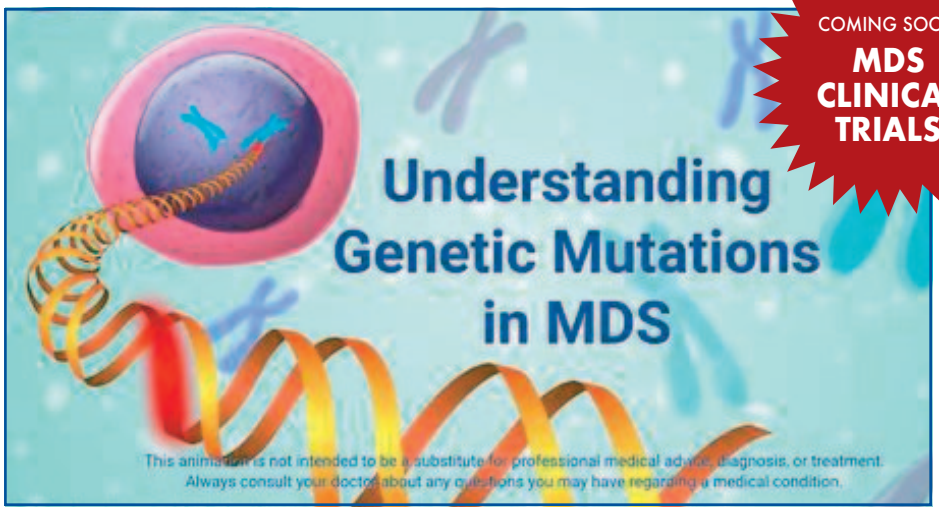
VIETNAM

National Institute of Hematology
and Blood Transfusion
Hanoi, Vietnam
Khanh Quoc Bach, MD, PhD

PATIENT RESOURCES

Have you checked out our YOU and MDS ANIMATED PATIENT VIDEO SERIES yet??

NEW 'YOU AND MDS' MODULE ALERT:
UNDERSTANDING GENETIC MUTATATIONS IN MYELODYSPLASTIC SYNDROMES (MDS)



This brand-new animated learning resource is the newest addition to our You and MDS series. It is intended for patients with MDS, as well as family members and caregivers. Learn about genetic changes in myelodysplastic syndromes (MDS), and the many different driver mutations that are associated with MDS. Some mutated genes are associated with lower-risk disease, while others may indicate greater risk. Your mutation profile can change over time, so it is important to repeat the testing at different stages of your treatment. The more you know about your genetic makeup in MDS, the more you will understand the outlook and, in some cases, the treatment that is most likely to be effective.

VISIT OUR WEBSITE:
WWW.YOUANDMDS.COM

THE ADDED BENEFITS OF CLINICAL TRIALS

If you are diagnosed with MDS, participating in a clinical trial may offer you a number of advantages in addition to the standard treatment. Through our partnership with our MDS Centers of Excellence and industry partners, patients have access to the latest clinical trials on the MDSF website here **https://www.mds-foundation.org/clinical-trial-announcements/.**

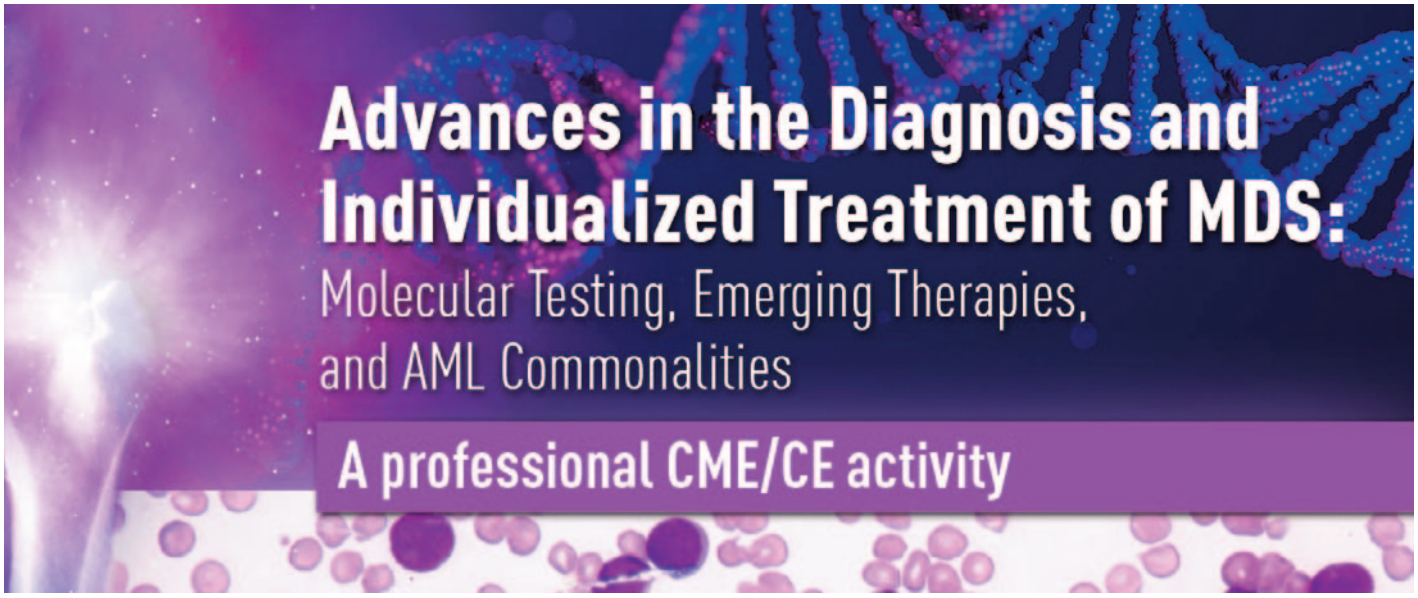
POTENTIAL BENEFITS INCLUDE:

- Working with top specialists who conduct research and are highly knowledgeable about the latest treatments.
- Being offered cutting-edge treatments not yet available to the general population that may help you live longer and/or improve your quality of life.
- Playing a meaningful role in a study that could help other patients in the future.

PLEASE VISIT OUR WEBSITE:
https://www.mds-foundation.org/wp-content/uploads/2022/02/LARGE-MDS-Insurance-Booklet-PRINT.pdf.

GUIDE TO ASSISTANCE PROGRAMS IN THE UNITED STATES

We have assembled a listing of assistance programs available to MDS patients. It is important to know that there is support for those who cannot afford medicine or other healthcare costs. We hope this new resource will be beneficial in helping you with your medical needs.



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Dr. Fransesc Sole
Dr. Alan F. List
Dr. Esther Olivia
Dr. Michael Pfeilstöcker
Dr. Guido Kobbe
Dr. Rafael Bejar
Dr. Sophia Park
Dr. Blanca Xicoy

LANGUAGE MODULE

English
German
French
Spanish
Portuguese
Italian

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https://www.igive.com
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NUTRITIONAL CONSIDERATIONS IN MDS

HILLARY SACHS, MS, RD, CSO, CDN
Board Certified Oncology Dietician

Myelodysplastic syndrome is a complex disorder that affects the bone marrow from making new blood cells normally. Signs and symptoms can vary from person to person. In general however, proper and adequate nutrition can aid the body's ability to regenerate new and healthy cells as best as possible.

MANAGING SYMPTOMS

Anemia

According to the Mayo Clinic, "anemia is a condition in which you don't have adequate healthy red blood cells to carry adequate oxygen to your tissues." In turn, this may make you feel tired or weak. Choosing nutrient dense foods rich in iron, B_{12} and folate can ensure that the body has all of the building blocks it needs for when it is able to produce new red blood cells.

These foods include::

- Beets and beet greens
- Dark green leafy vegetables like kale, spinach, broccoli, swiss chard
- Dark colored fruits like berries, cherries, figs and grapes
- Nuts like almonds, walnuts and brazil nuts
- Grass fed beef
- Black rice and quinoa
- *Bone broths*

(Note: Wash all produce well; if neutropenic, discuss with medical team.)

For people who need to absorb extra iron, here are a few tips:

1. Pair a source of iron with a source of vitamin C for extra absorption
   a. Peanut butter and strawberries on sprouted bread
   b. Brown rice, black beans and peppers
   c. Shrimp with lemon and lime
   d. Hamburger with tomato
2. Use a cast-iron skillet

PROPER AND ADEQUATE NUTRITION CAN AID THE BODY'S ABILITY TO REGENERATE NEW AND HEALTHY CELLS AS BEST AS POSSIBLE.

For people who are looking to minimize iron absorption due to iron overload after a transfusion, here are a few tips:

- Drink coffee with your meal
- Drink tea with your meal
- Eat a source of calcium with your meal

Neutropenia

According to the Mayo Clinic, "neutropenia is an abnormally low count of neutrophils, a type of white blood cell that helps fight off infections, particularly those caused by bacteria and fungi."

Since our white blood cells help to fight infection, it is important to follow the USDA's food safety precautions for people with cancer if your white blood cells are low: https://www.fda.gov/food/people-risk-foodborne-illness/food-safety-older-adults-and-people-cancer-diabetes-hivaids-organ-transplants-and-autoimmune

In addition, there are certain foods/supplements that may help to support our natural immunity.

Foods

Foods high in vitamin D: mushrooms, fish, sundried tomatoes, dairy/dairy alternatives
Foods high in zinc: mushrooms, cooked oysters, wheat germ, pumpkin seeds
Foods high in vitamin C: tomatoes, broccoli, peppers, cherries, strawberries, citrus
Foods high in selenium: brazil nuts, tuna (chunk light has least amount of mercury), mushrooms, chicken, turkey

Supplements

- Ginger-can thin blood, may decrease bioavailability of cyclosporine
- Elderberry-caution with drugs metabolized via CYP34A
- Astragalus-caution with lithium, may thin blood
- Reishi mushrooms-may thin blood; caution with autoimmune conditions
- Goldenseal -may interfere with INR tests; may increase bilirubin; inhibits CYP34A and CYP2D6

**According to MSKCC About Herbs and Botanicals*

(Note: always speak with your medical team before taking supplements!):

Thrombocytopenia

According to the Mayo clinic "thrombocytopenia is a condition in which you have a low platelet count. Platelets are colorless blood cells that help blood clot."

In order to help keep platelet counts up as high as possible, it is important to consider the following nutritional factors:

- Eat adequate amounts of protein. While protein needs fluctuate with age, medical condition and activity level, on average someone with MDS needs about 1.1-1.3 grams per kilogram of body weight of protein which is an increase from the standard 0.8-1.0 grams per kilogram of body weight, which the average person needs. 1.1-1.3 grams per kilogram amounts to 50-60 grams for a 100 pound person, 75-89 grams for a 150 pound person and 100-118 grams for a

200 pound person. Protein rich foods include animal products like dairy, chicken, fish, eggs, beef, lamb, etc. It also includes vegetarian options like tofu, beans, nuts and certain grains/seeds like quinoa and hemp.

- Consume adequate amounts of calcium and dark green vegetables. This may help provide baseline clotting factors.
- Consume sesame oil and pineapple (not necessarily eaten together). This tip is purely anecdotal claimed by many naturopaths. Unfortunately, more research needs to be done to understand if this is true and, if so, what the mechanisms are. However, there are not really any downsides to consuming these foods.

MINIMIZING RISKS FROM A NUTRITION PERSPECTIVE

While the cause of MDS is mainly unknown, the American Cancer Society put out a statement with regards to benzenes and blood cancers. They state: "Benzene is known to cause cancer, based on evidence from studies in both people and lab animals. The link between benzene and cancer has largely focused on leukemia and cancers of other blood cells." While benzene exposure is mainly related to cigarette smoke, there are other environmental exposures like petroleum. From a nutrition perspective, in 2005 the FDA conducted an investigation on sodas and diet sodas and found some brands had higher than acceptable amounts of bezenes in their beverages. Follow up investigations were conducted shortly thereafter to ensure companies complied with standards.

A HEALTHY DIET IS A KEY COMPONENT TO KEEPING WELL AS YOU TRANSITION INTO CANCER SURVIVORSHIP.

COMPONENTS TO LONGEVITY

A healthy diet is a key component to keeping well as you transition into cancer survivorship. The American Institute of Cancer Research has ten specific recommendations for cancer prevention. Highlights include being as lean as possible without being underweight, being physically active and consuming a wide variety of fruits and vegetables. Find a Certified Specialist in Oncology (CSO) in your area to discuss individual recommendations. Here's to your health!

FOR MORE INFORMATION

http://www.aicr.org/reduce-your-cancer-risk/recommendations-for-cancer-prevention/

Hillary Sachs has counseled and educated hundreds of people at various stages of their cancer journeys on the impact their nutrition has on their treatment and overall wellbeing. She offers oncology focused nutritional counseling aligned with HAES and intuitive eating.

A NEW PARTNERSHIP

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

OFFICIAL JOURNALS OF THE MDS FOUNDATION

Leukemia Research Reports

Leukemia Research
Clinical and Laboratory Studies

60% MDSF Professional Members receive a **SUBSCRIPTION DISCOUNT – ANNUALLY**

MDS PROFESSIONAL MEMBERSHIP OPTIONS – JOIN NOW

https://www.mds-foundation.org/professional-annual-membership-application/

$50 ***Community Professional Membership***

Includes discounted registration rates at MDSF meetings, 60% annual subscription discount to *Leukemia Research*, as well as access to MDSF resources for distribution to your patients.

$250 ***Change the Future of MDS Professional Membership***

Change the Future of MDS Professional Membership (Includes discounted registration rates at MDSF meetings, 60% annual subscription discount to *Leukemia Research*, access to MDSF resources for distribution to your patients, as well as the opportunity to present at MDSF patient events in your region). In addition, $50 of your membership will help support a Professional outside of the United States that represents a CoE in financial need. Member names are listed on the MDSF website.

2023 PATIENT FORUMS

FREE MEETINGS FOR MDS PATIENTS AND THEIR CAREGIVERS

Whether you are a newly diagnosed patient, a long-term survivor, or caregiver, our free one-day live in-person forums will have something for you. Ongoing meetings addressing quality of life issues for MDS patients will occur in seven cities around the world in 2023. A global patient forum will be held alongside our 17th International Congress on MDS in Marseille, France. Check our website and Facebook for updates.

LEARN MORE AT: **www.mds-foundation.org/patient-and-family-forums**

Many patients and caregivers have never met another person diagnosed with MDS until they connected with them at one of our forums. If you've never attended one, 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. Not only will you find answers, support and hope for MDS but you will learn tips and strategies for patients and caregivers *LIVING* with MDS.

DON'T MISS OUT ON THESE INFORMATIVE, FREE EVENTS

DOWNLOAD OUR MOBILE APP!

MDS FOUNDATION APP

HAVE MDS INFORMATION AT YOUR FINGERTIPS!

This app provides patients, caregivers, and healthcare providers with quick access to the important services that the MDS Foundation provides. These services include our worldwide Centers of Excellence, upcoming Patient Forums and Events, as well as our numerous online resources.

Available in the Google Play Store and iTunes

ANDROID APP ON Google play

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MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

2023 WEBINARS FOR MDS PATIENTS & CAREGIVERS

WE ARE VIRTUAL!

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

We have planned a comprehensive series of webinars for 2023 bringing experts and the MDS community together to provide educational information, best practices, tools, and resources

Whether you are a newly diagnosed patient, a long-term survivor, or caregiver, our webinar series will have something for you.

We have collaborated with renowned hematology professionals who will address key topics and questions you may have using language that is easy to understand in a 90-minute format that will include live Q&A opportunities for all participants.

REGISTER NOW!
MDS WEBINARS

MISSED OUR LIVE WEBINAR?
VIEW PREVIOUS LIVE WEBINARS AT A TIME THAT IS CONVENIENT FOR YOU!

https://www.mds-foundation.org/2023-webinars-for-mds-patients-caregivers

"Aren't you scared?" a young person asked me. Sometimes, yes. I try to remember to pray when I am afraid. The MDS Foundation sponsors webinars that have helped me learn a lot. I remind myself that I am living with MDS, not dying with it."

SUBSCRIBE: MDS FOUNDATION PODCASTS

THIS PODCAST SERIES PROVIDES IMPORTANT UP-TO-THE-MINUTE INFORMATION ON MDS INCLUDING DIAGNOSIS, TREATMENT AND CLINICAL RESEARCH.

The explosion of information on MDS forces us to seek novel, alternative ways to distribute it. Podcasts gives us an easy and popular way to communicate this information in a short time.

Listen on Apple Podcasts
LISTEN ON Spotify
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Castbox
LISTEN ON STITCHER

SUBSCRIBE!

MDS PROFESSIONAL REPORT

SEASON 2: EPISODE 1: *MDS in ASH 2021 – Are We Already in the Molecular Era?*

Drs. Moshe Mittelman, of The Tel Aviv Sourasky Medical Center, and Drorit Merkel, of the Sheba Medical Center, both from Tel Aviv University, Israel, discuss several important presentations from the recent 2021 ASH meeting.

SEASON 2: EPISODE 2: *The Role of Genetics in MDS Management*

Drs. Rafael Bejar (San Diego) and Moshe Mittelman (Tel Aviv) discuss several papers highlighting the role of genetics in MDS diagnosis, follow up and prediction of treatment. They also discuss the role of the newly approved luspatercept in the treatment of anemic transfusion-dependent patients with lower-risk MDS.

MDS PATIENT & FAMILY REPORT

This new initiative of the MDS Foundation is devoted to MDS patients, family members and caregivers. In each episode, experts in the field will discuss novel information on MDS, such as new diagnostic techniques, new therapies etc. They will also answer frequently asked questions.

SEASON 1: EPISODE 1: *MDS is Already in the Genetic Era*

The first episode of this program is a conversation between Prof. Guillermo Sanz from Valencia, Spain and Prof. Moshe Mittelman from Tel Aviv, Israel, discussing several issues relevant for patients, families and other stakeholders interested in myelodysplastic syndromes.

SEASON 1: EPISODE 2: *Personalized Treatment of MDS*

Drs. Rafael Bejar (San Diego) and Moshe Mittelman (Tel Aviv) discuss the trend towards adjusting the appropriate treatment to the particular MDS patient, a trend that is associated with higher rate of successful treatments and less toxicity. They also address several frequently asked questions.

IN THE NEWS

PRESS RELEASES

BRISTOL MYERS SQUIBB ANNOUNCES POSITIVE TOPLINE RESULTS OF PHASE 3 COMMANDS TRIAL

Reblozyl, the first erythroid maturation agent, met primary and key secondary endpoints in the first-line treatment of patients with very low/low/intermediate-risk myelodysplastic syndromes

PRINCETON, NJ. OCTOBER 31, 2022 (BUSINESS WIRE). Bristol Myers Squibb (NYSE:BMY) today announced the COMMANDS study, a Phase 3, open-label, randomized trial evaluating *Reblozyl*® (luspatercept-aamt), met its primary endpoint, demonstrating a highly statistically significant and clinically meaningful improvement in red blood cell transfusion independence (RBC-TI) with concurrent hemoglobin (Hb) increase in the first-line treatment of adult patients with very low-, low- or intermediate-risk myelodysplastic syndromes (MDS) who require RBC transfusions. This result was based on a pre-specified interim analysis conducted through an independent review committee. Safety results in the trial were consistent with the safety profile of *Reblozyl* previously demonstrated in the MEDALIST study (NCT02631070), and no new safety signals were reported.

"While advancements have been made in the treatment of anemia for patients with myelodysplastic syndromes, there remains a significant need for new and better first-line treatment options for patients with transfusion-dependent MDS," said Noah Berkowitz, M.D., Ph.D., senior vice president, Hematology Development, Bristol Myers Squibb. "We are pleased with the positive results of the COMMANDS study and look forward to presenting these important data."

Bristol Myers Squibb will complete a full evaluation of the COMMANDS data and work with investigators to present detailed results at an upcoming medical meeting, as well as discuss these results with health authorities. Bristol Myers Squibb thanks the patients and investigators who are participating in the COMMANDS clinical trial.

Reblozyl is being developed and commercialized through a global collaboration with Merck following Merck's acquisition of Acceleron Pharma, Inc. in November 2021.

ABOUT COMMANDS

COMMANDS (NCT03682536) is a Phase 3, open-label, randomized study evaluating the efficacy and safety of Reblozyl versus epoetin alfa, for the treatment of anemia due to very low-, low- or intermediate-risk (IPSS-R) myelodysplastic syndrome (MDS) in patients who are red blood cell (RBC) transfusion dependent and were erythropoiesis stimulating agent (ESA) naïve.

The primary endpoint evaluated in this study is RBC transfusion independence (RBC-TI) for 12 weeks with a mean hemoglobin increase ≥1.5 g/dL. Key secondary endpoints include RBC-TI for 24 weeks, RBC-TI ≥12 weeks and erythroid response of at least 8 weeks during weeks 1-24 of the study.

ABOUT REBLOZYL® (luspatercept-aamt)

Reblozyl, a first-in-class therapeutic option, promotes late-stage red blood cell maturation in animal models. *Reblozyl* is being developed and commercialized through a global collaboration with Merck following Merck's acquisition of Acceleron Pharma, Inc. in November 2021. Reblozyl is currently approved in the U.S. for the treatment of:

- anemia in adult patients with beta thalassemia who require regular red blood cell transfusions, and
- anemia failing an erythropoiesis stimulating agent and requiring 2 or more red blood cell units over 8 weeks in adult patients with very low- to intermediate-risk myelodysplastic syndrome with ring sideroblasts (MDS-RS) or with myelodysplastic/ myeloproliferative neoplasm with ring sideroblasts and thrombocytosis (MDS/MPN-RS-T).

Reblozyl is not indicated for use as a substitute for red blood cell transfusions in patients who require immediate correction of anemia.

ABOUT BRISTOL MYERS SQUIBB

Bristol Myers Squibb is a global biopharmaceutical company whose mission is to discover, develop and deliver innovative medicines that help patients prevail over seriousdiseases. For more information about Bristol Myers Squibb,visit us at BMS.com or follow us on LinkedIn, Twitter, YouTube, Facebook and Instagram.

BRISTOL MYERS SQUIBB DATA AT ASH 2022 HIGHLIGHT INNOVATIVE THERAPEUTIC PLATFORMS ACROSS A RANGE OF BLOOD DISEASES

New data from our multiple myeloma portfolio across targets and molecular approaches show significant progress toward our goal of transforming the treatment paradigm and improving outcomes for patients

Multiple first disclosures including preliminary Phase 1 data for subcutaneous administration of bispecific T cell engager alnuctamab in heavily pretreated multiple myeloma, preliminary Phase 1 results for GPRC5D CAR T in relapsed/refractory multiple myeloma and first results from the Phase 2 KarMMa-2 trial evaluating Abecma in high-risk multiple myeloma

New data for CD19-directed CAR T cell therapy Breyanzi, including longer-term follow up from pivotal Phase 3 TRANSFORM study in second-line relapsed or refractory large B-cell lymphoma

PRINCETON, NJ. NOVEMBER 22, 2022 (BUSINESS WIRE). Bristol Myers Squibb (NYSE:BMY) today announced the presentation of research across its hematology portfolio at the 64th American Society of Hematology (ASH) Annual Meeting and Exposition, which will take place in New Orleans, Louisiana, and virtually, from December 10-13, 2022. Data from more than 100 company-sponsored studies will be featured, including 34 oral presentations, highlighting the range of modalities, targets and research platforms the company is advancing and showcasing our commitment to scientific progress across hematologic diseases.

"Our presence at ASH underscores the transformational potential of our diverse pipeline, poised to deliver the next wave of advances in hematology," said Samit Hirawat, M.D., executive vice president, chief medical officer, Global Drug Development, Bristol Myers Squibb. "These exciting data, spanning a variety of modalities and targets, demonstrate significant progress toward our goals of improving long-term outcomes across patient

populations and finding solutions in important areas of remaining need."

Key data being presented by Bristol Myers Squibb and its partners at the 2022 ASH Annual Meeting and Exposition include:

CELL THERAPY

- Updated data including longer-term follow up from the primary analysis of the Phase 3 TRANSFORM study evaluating *Breyanzi*® (lisocabtagene maraleucel) versus the standard of care as a second-line treatment in relapsed or refractory large B-cell lymphoma (LBCL)
- Updated data from the primary analysis of the Phase 2 OUTREACH study evaluating Breyanzi as a third-line plus treatment in relapsed or refractory LBCL in the community setting
- Safety and efficacy results of the match-adjusted indirect comparison of the TRANSFORM versus ZUMA-7 studies evaluating Breyanzi versusaxicabtagene ciloleucelin the second-line setting in relapsed or refractory LBCL
- Two first disclosures of results from cohorts 2a and 2c of the Phase 2 KarMMa-2 trial evaluating *Abecma* in high-risk multiple myeloma
- First disclosure of preliminary Phase 1 results for GPRC5D chimeric antigen receptor (CAR) T cell therapy in patients with relapsed/refractory (R/R) multiple myeloma, including patients previously treated with a B-cell maturation antigen (BCMA)-directed CAR T cell therapy

HEMATOLOGY

- Multiple analyses of *Reblozyl*® (luspatercept-aamt), including overall survival data from the Phase 3 MEDALIST study in lower-risk myelodysplastic syndromes and real-world, longer-term results from the Phase 2 BEYOND study in beta thalassemia
- Multiple analyses of I*nrebic*® (fedratinib), including the primary analysis of safety and efficacy from the Phase 3b FREEDOM trial in intermediate- or high-risk myelofibrosis
- Longitudinal analyses of acute myeloid leukemia gene mutations with *Onureg*® (azacitidine tablets) from the Phase 3 QUAZAR® AML-001 study

EARLY PIPELINE

- First disclosure of preliminary results from the dose escalation and expansion components of the Phase 1 CC-93269 MM-001 study, evaluating subcutaneous bispecific T cell engager alnuctamab in heavily pretreated multiple myeloma
- First results from dose expansion cohort of the CC-92480 Phase 1/2 MM-001 study, evaluating CELMoDTM agent mezigdomide with dexamethasone in patients with R/R multiple myeloma
- Results from post-BCMA cohort of the CC-220 Phase 1/2 MM-001 study, evaluating CELMoD agent iberdomide with dexamethasone in patients with R/R multiple myeloma previously treated with a BCMA-directed therapy
- First results from a Phase 1/2 study evaluating BMS-986158, a potent Bromodomain and Extraterminal (BET) inhibitor, as monotherapy and in combination with ruxolitinib or Inrebic in intermediate- or high-risk myelofibrosis

ABOUT BREYANZI U.S. INDICATION

Breyanzi is a CD-19 directed chimeric antigen receptor (CAR) T cell therapy, administered as a defined composition to reduce variability of the CD8 and CD4 component dose. *Breyanzi* has a 4-1BB costimulatory domain which enhances the expansion and persistence of the CAR T cells. Breyanzi was previously approved by the U.S. Food and Drug Administration for the treatment of adult patients with relapsed or refractory LBCL after two or more lines of systemic therapy, including diffuse large B-cell lymphoma (DLBCL) not otherwise specified (including DLBCL arising from indolent lymphoma), high-grade B-cell lymphoma, primary mediastinal large B-cell lymphoma, and follicular lymphoma grade 3B. Breyanzi is available only through a restricted program under a Risk Evaluation and Mitigation Strategy (REMS) called the BREYANZI REMS.

Breyanzi is also approved in Europe, Switzerland, Canada and Japan for relapsed and refractory LBCL after two or more lines of systemic therapy. Bristol Myers Squibb's clinical development program for *Breyanzi* includes clinical studies in earlier lines of treatment for patients with relapsed or refractory LBCL and other types of lymphoma. For more information, visit clinicaltrials.gov.

GERON ANNOUNCES POSITIVE TOP-LINE RESULTS FROM IMERGE PHASE 3 TRIAL OF IMETELSTAT IN LOWER RISK MDS

- *Trial met primary 8-week transfusion independence (TI) endpoint and key secondary 24-week TI endpoint with highly statistically significant and clinically meaningful improvements*
- *Median TI duration approaching one year for imetelstat 8-week TI responders and 1.5 years for imetelstat 24-week TI responders*
- *Statistically significant and clinically meaningful efficacy results achieved across key MDS subtypes, including ring sideroblast (RS+/RS-) status, high and very high transfusion burden and Low and Intermediate-1 IPSS risk categories*
- *Safety results consistent with prior imetelstat clinical experience with no new safety signals*
- *Clinical and molecular evidence support the potential for MDS disease modification*
- *Request for rolling submission of U.S. New Drug Application (NDA) granted and 2023 plans on target for regulatory submissions in the U.S. and EU*

FOSTER CITY, CA. JANUARY 4, 2023 (BUSINESS WIRE). Geron Corporation (Nasdaq: GERN), a late-stage clinical biopharmaceutical company, today announced positive top-line results from its IMerge Phase 3 clinical trial evaluating the Company's first-in-class telomerase inhibitor, imetelstat, in lower risk myelodysplastic syndromes (MDS) patients who are relapsed, refractory or ineligible for erythropoiesis stimulating agents (ESAs). The trial met its primary efficacy endpoint of 8-week TI and a key secondary endpoint of 24-week TI, demonstrating highly statistically significant and clinically meaningful benefit of imetelstat versus placebo with no new safety signals and safety results consistent with prior imetelstat clinical trials.

"Today is a great day for lower risk MDS patients who are living with the burden of transfusions. The results from the IMerge Phase 3 study were resoundingly positive, presenting compelling durability of transfusion independence, delivering on the promise of

imetelstat and telomerase inhibition for these patients," said John A. Scarlett, M.D., Geron's Chairman and Chief Executive Officer. "This milestone is the first of many upcoming catalysts for Geron, with planned U.S. and EU regulatory submissions in 2023, as well as preparations for a potential U.S. commercial launch. In addition, in 2024, we expect an interim analysis of the IMpactMF Phase 3 trial of imetelstat in relapsed/refractory myelofibrosis."

SUMMARY OF TOP-LINE RESULTS: PRIMARY 8-WEEK TI ENDPOINT AND KEY 24-WEEK TI SECONDARY ENDPOINT MET WITH STATISTICAL SIGNIFICANCE AND MEANINGFUL CLINICAL IMPROVEMENTS

Significant and durable transfusion independence achieved with imetelstat versus placebo

IMerge Phase 3 is a double-blind, 2:1 randomized, placebo-controlled clinical trial to evaluate imetelstat in patients with IPSS Low or Intermediate-1 risk (lower risk) transfusion dependent MDS who were relapsed after, refractory to, or ineligible for, ESA treatment, had not received prior treatment with either a hypomethylating agent (HMA) or lenalidomide and were non-del(5q).

Table 1 summarizes the top-line efficacy results from the primary analysis of data from IMerge Phase 3, which showed a highly statistically significant and clinically meaningful difference between imetelstat and the placebo comparator arm for the primary endpoint of 8-week TI and key secondary endpoint of 24-week TI. With a clinical data cut-off occurring in October 2022, median time on study and median time on treatment for patients on imetelstat was approximately 20 months and 8 months, respectively, and approximately 18 months and 7 months for placebo, respectively.

TRANSFUSION INDEPENDENCE ACHIEVED BROADLY ACROSS LOWER RISK MDS SUBTYPES

As shown in Table 2, statistically significant ($p<0.05$) 8-week TI was demonstrated with imetelstat versus placebo across lower risk MDS subtypes, including RS+ and RS- status, high and very high transfusion burden and IPSS Low and Intermediate-1 risk status, with similar 8-week TI responses seen for imetelstat within each subtype category.

TABLE 1.

	Imetelstat (n=118)	Placebo (n=60)	P-value*
8-week TI, n (%)	47 (39.8)	9 (15.0)	<0.001
95% confidence interval	(30.9, 49.3)	(7.1, 26.6)	
24-week TI, n (%)	33 (28.0)	2 (3.3)	<0.001
95% confidence interval	(20.1, 37.0)	(0.4, 11.5)	

*Cochran Mantel Haenszel test stratified for prior RBC transfusion burden (≤6 units or >6 units of RBCs/8 weeks) and baseline IPSS risk score (Low or Intermediate-1)

Highly statistically significant ($p<0.001$; hazard ratio 0.23) durable transfusion independence for 8-week TI responders was achieved with a median TI duration approaching one year for imetelstat, compared to approximately 13 weeks for placebo, using Kaplan-Meier estimates. The median TI duration was approximately 1.5 years (80 weeks) for imetelstat 24-week TI responders.

TABLE 2.

8-Week TI	Imetelstat n (%)	Placebo n (%)	Difference (95% CI)	P-value*
Overall	47/118 (39.8)	9/60 (15.0)	24.8 (9.9, 36.9)	<0.001
WHO category				
RS+	33/73 (45.2)	7/37 (18.9)	26.3 (5.9, 42.2)	0.016
RS-	14/44 (31.8)	2/23 (8.7)	23.1 (-1.3, 40.6)	0.038
Transfusion burden				
4-6 units	28/62 (45.2)	7/33 (21.2)	23.9 (1.9, 41.4)	0.027
>6 units	19/56 (33.9)	2/27 (7.4)	26.5 (4.7, 41.8)	0.023
IPSS risk category				
Low	32/80 (40.0)	8/39 (20.5)	19.5 (-0.1, 35.2)	0.034
Intermediate-1	15/38 (39.5)	1/21 (4.8)	34.7 (8.8, 52.4)	0.004

* Cochran Mantel Haenszel test stratified for prior RBC transfusion burden (≤6 units or >6 units of RBCs/8 weeks) and baseline IPSS risk score (Low or Intermediate-1)

INCREASE IN HEMOGLOBIN LEVELS, REDUCTION IN RBC TRANSFUSIONS AND HEMATOLOGIC IMPROVEMENT-ERYTHROID (HI-E)

Mean hemoglobin levels in imetelstat patients increased significantly ($p<0.001$) over time compared to placebo patients. For patients achieving 8-week TI, median increases in hemoglobin were 3.6 g/dL for imetelstat and 0.8 g/dL for placebo. Imetelstat patients also experienced a statistically significant ($p=0.042$) and clinically meaningful mean reduction in RBC transfusion units compared to placebo.

A highly statistically significant ($p<0.001$) HI-E rate was achieved for imetelstat (42.4%) versus placebo (13.3%) using the IWG 2018 criteria for HI-E. The original IMerge protocol was finalized in 2015, and applying the IWG 2006 HI-E criteria in use at that time, the difference between the imetelstat and placebo patients was not statistically significant ($p=0.112$). The current IWG 2018 HI-E criteria places greater emphasis on durability by measuring response for ≥16 weeks, rather than ≥8 weeks as specified by the IWG 2006 criteria.

CLINICAL AND MOLECULAR EVIDENCE SUPPORTING THE POTENTIAL FOR MDS DISEASE MODIFICATION WITH IMETELSTAT

Clinical and molecular evidence supporting the potential for MDS disease modification with imetelstat included a one-year median TI duration for imetelstat 8-week TI responders, a median rise of 3.6 g/dL in hemoglobin levels in those same patients and ≥50% variant allele frequency decreases in SF3B1, TET2, DNMT3A and ASXL1 mutations.

"The notable results from IMerge Phase 3 underscore our belief that, with the unique mechanism of action of imetelstat as a telomerase inhibitor, the drug has the potential to become a first-in-class therapy for lower risk MDS patients. The meaningful clinical results observed in the trial, including duration of TI, increases in hemoglobin levels, decreases in transfusions and reductions in mutation burdens, suggest imetelstat treatment may be altering the course of the disease. We look forward to presenting additional data from the trial at medical meetings later this year to further develop the evidence for potential disease modification previously observed in Phase 2 trials in both lower risk MDS and

relapsed/refractory MF," said Faye Feller, M.D., Chief Medical Officer of Geron. "I would also like to express my deep appreciation to the Geron employees, past and present, as well as all of the patients and their families, the clinicians, study coordinators and site personnel, whose participation in this trial was integral to obtaining the results we are presenting today."

SAFETY RESULTS CONSISTENT WITH PRIOR CLINICAL EXPERIENCE WITH IMETELSTAT

The treatment emergent adverse events (TEAEs) observed in IMerge Phase 3 were consistent with the known safety profile of imetelstat from prior clinical trials and no new safety signals were found. Overall treatment discontinuation rates were consistent between the imetelstat and placebo groups (77.1% vs. 76.3%, respectively). Treatment discontinuation rates related to lack of efficacy were higher for the placebo group (42.4%) versus imetelstat (23.7%), and lower for adverse events between the placebo and imetelstat groups (0.0% vs. 16.1%, respectively).

The most common non-hematologic TEAEs (≥10%) in the imetelstat group included asthenia, COVID-19, peripheral edema, headache, diarrhea and alanine amino-transferase increase. Grade 3 liver function test (LFT) elevations reported in the trial were transient and reversible to Grade 2 or lower, with no cases of liver test elevations consistent with Hy's Law or Drug-Induced Liver Injury observed.

The most frequent hematologic TEAEs were Grade 3/4 thrombocytopenia (61.9% imetelstat vs. 8.5% placebo) and neutropenia (67.8% imetelstat vs. 3.4% placebo). Clinical consequences from cytopenias, such as > Grade 3 bleeding events, infections and febrile neutropenia, were similar between the imetelstat and placebo groups. Furthermore, the median duration was shorter for imetelstat for thrombocytopenia (1.4 weeks for imetelstat vs. 2.0 weeks for placebo) and for neutropenia (1.9 weeks for imetelstat vs. 2.2 weeks for placebo). In addition, resolution of Grade 3/4 cytopenias to Grade 2 or lower by laboratory assessment within four weeks was higher for imetelstat, both for thrombocytopenia (86.3% for imetelstat vs. 44.4% for placebo) and neutropenia (81.0% for imetelstat vs. 50.0% for placebo).

"The IMerge Phase 3 efficacy results illustrate the depth, breadth and durability of transfusion independence potentially achievable with imetelstat treatment, which could be practice changing, if approved. These results are especially encouraging, because today we have limited treatment options for lower risk MDS patients that provide broad and durable transfusion independence," said Uwe Platzbecker, M.D., a principal investigator of IMerge Phase 3. "With regards to the safety results, cytopenias were manageable and reversible. Importantly for hematologists, who are accustomed to managing cytopenias, clinical consequences were limited and similar to placebo treated patients. As a once per month out-patient IV therapy, imetelstat will hopefully become a novel treatment option for lower risk MDS patients in the near future."

PLANNED NEXT STEPS

In light of the positive top-line results from IMerge Phase 3, combined with data from earlier clinical trials, the Company plans to submit an NDA in the U.S. in mid-2023 and a Marketing Authorization Application (MAA) in the EU in the second half of 2023. With Fast Track designation for imetelstat from the U.S. Food and Drug Administration for the treatment of adult patients with transfusion dependent anemia due to Low or Intermediate-1 risk MDS that is not associated with del(5q) who are refractory or resistant to an ESA, a request for rolling submission of the NDA was submitted and has been granted.

Geron also plans to present additional data from IMerge Phase 3 at medical meetings later this year, including data relating to potential correlations of decreases in mutation burden and abnormal cytogenetic clones with clinical responses, patient reported outcomes, hTERT and telomerase activity biomarker data and continued follow-up of durability of transfusion independence, that may be indicative of the potential for disease modification with imetelstat.

Geron is preparing for an anticipated commercial launch of imetelstat in lower risk MDS in the first half of 2024 in the U.S. and by the end of 2024 in the EU, assuming regulatory approvals are granted.

ABOUT IMERGE PHASE 3

The Phase 3 portion of the IMerge Phase 2/3 study is a double-blind, 2:1 randomized, placebo-controlled clinical trial to evaluate imetelstat in patients with IPSS Low or Intermediate-1 risk (lower risk) transfusion dependent MDS who were relapsed after, refractory to, or ineligible for, erythropoiesis stimulating agent (ESA) treatment, had not received prior treatment with either a HMA or lenalidomide and were non-del(5q). To be eligible for IMerge Phase 3, patients were required to be transfusion dependent, defined as requiring at least four units of packed red blood cells (RBCs), over an eight-week period during the 16 weeks prior to entry into the trial. The primary efficacy endpoint of IMerge Phase 3 is the rate of RBC-TI lasting at least eight weeks, defined as the proportion of patients without any RBC transfusion for at least eight consecutive weeks since entry to the trial (8-week TI). Key secondary endpoints include the rate of RBC-TI lasting at least 24 weeks (24-week TI), the duration of TI and the rate of hematologic improvement erythroid (HI-E), which defined as a rise in hemoglobin of at least 1.5 g/dL above the pretreatment level for at least eight weeks or a reduction of at least four units of RBC transfusions over eight weeks compared with the prior RBC transfusion burden. A total of 178 patients were enrolled in IMerge Phase 3 across North America, Europe, Middle East and Asia.

ABOUT IMETELSTAT

Imetelstat is a novel, first-in-class telomerase inhibitor exclusively owned by Geron and being developed in hematologic malignancies. Data from non-clinical studies and clinical trials of imetelstat provide strong evidence that imetelstat targets telomerase to inhibit the uncontrolled proliferation of malignant stem and progenitor cells in myeloid hematologic malignancies resulting in malignant cell apoptosis and potential disease-modifying activity. Imetelstat has been granted Fast Track designation by the U.S. Food and Drug Administration for both the treatment of adult patients with transfusion dependent anemia due to Low or Intermediate-1 risk MDS that is not associated with del(5q) who are refractory or resistant to an erythropoiesis stimulating agent, and for adult patients with Intermediate-2 or High-risk MF whose disease has relapsed after or is refractory to janus associated kinase (JAK) inhibitor treatment.

ABOUT GERON

Geron is a late-stage biopharmaceutical company pursuing therapies with the potential to extend and enrich the lives of patients living with hematologic malignancies. The Company's investigational first-in-class telomerase inhibitor, imetelstat, harnesses Nobel Prize-winning science in a treatment that may alter the underlying drivers of disease. Geron currently has a Phase 3 clinical trial underway evaluating imetelstat in each of: (i) lower risk myelodysplastic syndromes (LR MDS), and (ii) relapsed/refractory myelofibrosis (MF). To learn more, visit www.geron.com or follow us on LinkedIn.

SYROS RECEIVES FAST TRACK DESIGNATION FROM THE FDA FOR TAMIBAROTENE FOR THE TREATMENT OF HIGHER-RISK MYELODYSPLASTIC SYNDROME

Currently evaluating tamibarotene in combination with azacitidine pivotal SELECT-MDS-1 Phase 3 clinical trial in newly diagnosed HR-MDS patients with RARA gene overexpression

CAMBRIDGE, MA. JANUARY 26, 2023 (BUSINESS WIRE). Syros Pharmaceuticals, Inc. (NASDAQ:SYRS), a biopharmaceutical company committed to advancing new standards of care for the frontline treatment of hematologic malignancies, today announced that the United States Food and Drug Administration (FDA) has granted Fast Track Designation to tamibarotene for the treatment of higher-risk myelodysplastic syndrome (HR-MDS). Tamibarotene, an oral first-in-class selective retinoic acid receptor alpha (RARα) agonist, is currently being evaluated in combination with azacitidine for the treatment of newly diagnosed HR-MDS patients with RARA gene overexpression.

"Receipt of Fast Track designation for tamibarotene underscores both the potential of tamibarotene and the unmet need for HR-MDS patients, who have a poor prognosis due to the progressive nature of the disease," said David A. Roth, M.D., Chief Medical Officer of Syros Pharmaceuticals. "No new therapies beyond hypomethylating agents have been approved since 2006, and approximately half of all patients diagnosed with HR-MDS patients ultimately progress to AML. We are grateful for the opportunity to potentially expedite the delivery of tamibarotene as a new standard of care for this population."

Fast Track is a process designed by the FDA to facilitate the development and expedite the review of drug candidates intended to treat serious conditions and for which nonclinical or clinical data demonstrate the potential to address unmet medical need. The purpose is to help speed development of new drugs, making them available to the patient earlier. A therapeutic candidate that receives Fast Track designation may be eligible for more frequent interactions with the FDA to discuss the therapeutic candidate's development plan. Therapeutic candidates with Fast Track designation may also be eligible for priority review and accelerated approval if supported by clinical data.

Syros is evaluating tamibarotene in combination with azacitidine in newly diagnosed HR-MDS patients with RARA overexpression in the ongoing SELECT MDS-1 Phase 3 trial. This randomized, double-blind, placebo-controlled study is intended to enroll 190 patients. Syros currently has over 75 clinical sites open for recruitment in 12 countries. Syros expects to complete patient enrollment in SELECT-MDS-1 in the fourth quarter of 2023, with pivotal data expected in the third quarter of 2024.

Syros is also evaluating tamibarotene in combination with venetoclax and azacitidine in newly diagnosed unfit AML patients with RARA overexpression, with initial data from the randomized portion of the SELECT-AML-1 Phase 2 trial expected in the fourth quarter of 2023 and additional data in 2024.

ABOUT SYROS PHARMACEUTICALS

Syros is committed to developing new standards of care for the frontline treatment of patients with hematologic malignancies. Driven by the motivation to help patients with blood disorders that have largely eluded other targeted approaches, Syros is advancing a robust late-stage clinical pipeline, including tamibarotene, a first-in-class oral selective RARα agonist in patients with higher-risk myelodysplastic syndrome and acute myeloid leukemia with RARA gene overexpression, and SY-2101, a novel oral form of arsenic trioxide in patients with acute promyelocytic leukemia. Syros is also seeking partnerships for SY-5609, a highly selective and potent CDK7 inhibitor in clinical development for the treatment of select solid tumors, and multiple preclinical programs in oncology and monogenic diseases. For more information, visit www.syros.com and follow us on Twitter (@SyrosPharma) and LinkedIn.

Connecting
MDS COMMUNITIES

We are stronger together in the fight against MDS

We believe that the MDS Foundation is the heart of the MDS community, bringing together patients, caregivers, families, and physicians to take on this disease together. To be more inclusive of our community, we are discontinuing patient memberships* because we're all one big MDS family, connected through diagnosis and beyond. We will continue to cater to all the members of our community and provide support and resources for education, advocacy, and treatment research.

Join our community to stay connected, receive updates, and learn about the ways you can get involved!

SIGN-UP FOR E-NEWS @MDS-FOUNDATION.ORG

**Professional memberships will continue to enable the MDS Foundation to provide discounted registration rates and subscriptions*

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

HOPE & DETERMINATION

MARK FIXLER

Highland Heights, OH

The month was February 2019 and I had gone through a battery of tests for about two months because of a very low platelet count when my wife and I received the diagnosis of MDS. We were both devastated after this condition was explained to us. I was very fortunate that I was asymptomatic. The doctor explained there was treatment, but the treatment would not cure me, only hopefully put me in remission. The only option for a cure was a bone marrow transplant. Unfortunately, due to varying circumstances, no family members were even considered to be a match. We left the doctor's office devastated. Since faith has always been a big part of how I live my life, I remember going to work later that day and called my Rabbi. I told him I just received some very bad news. It took him about 30 minutes to come and see me. He saw I was very upset. I was told I had about 3.8 years to live with the treatment. All I could think about was my wife and son. Something very positive came out of that conversation. I knew it was all about time. He was going to pray for me, and I was going to pray as well. I couldn't change my diagnosis, but I could change how I would react to it. I made up my mind that day I needed to be strong physically as well as spiritually and mentally. For my age of almost 63, I was in good shape. Starting that weekend, I began to do pullups. I wanted to add one more every day. The following Monday I began the shots. While I was busy trying to get stronger, my wife was busy finding out all she could about MDS, which led us to the MDS Foundation. The information and support provided was invaluable. Being aware of clinical trials and other patients' stories gave us hope. I was still asymptomatic and was able to live a normal life continuing to exercise regularly slowly and steadily increasing my physical strength. I was fortunate to be able to tolerate the treatment with little to no side effects. It was very important for me to stay strong in every

aspect. My wife was very encouraging and helpful working with the hospital and every other aspect of trying to help me get over this condition. The doctors had me take a test for Be the Match and unfortunately no match was found. During the first year of treatment my other blood levels stayed within the normal range. Platelets increased a little. In February of 2020, my blood levels started to change. Slowly getting lower and lower. In November of 2020, my chest was not feeling right. I was becoming short of breath. The next blood test showed that my hemoglobin was down to 5.9. That's when the transfusions started. Things did not look good. In January of 2021, my oldest brother unexpectedly passed away and in March my father passed away. At that point, I was receiving weekly transfusions. However, I still felt okay. I was able to continue working.

By evening, the fatigue would set in. My wife insisted I go for a second opinion to see if there was a trial I could get into. She made an appointment with the Cleveland Clinic. We had all the records sent to them for review. They felt the treatment I was getting was appropriate. They wanted to send my information to the head of the bone marrow transplant team. We met with the doctor. Based on my health, she felt I would be a good candidate for a bone marrow transplant, provided they could find a donor. After a couple of months, I received a call from the doctor telling me she may have a match. I called my wife and she set up the testing that needed to be done. I had a good feeling about this. As I mentioned before, my wife was the rock that took care of all appointments, etc. so I could concentrate on working and keeping strong. After extensive testing for me and the potential donor, the doctor determined this was a good enough match. At that point, you can only imagine the emotions. I now had to prepare my body for the new cells. My wife and I went to a friend's home for a birthday party and there was a transplant doctor from another hospital. Our friends mentioned to him about my condition. He took one look at me and said this is going to work. He said when an immigrant comes to this country it takes them about two years to get acclimated. The same will be for your new cells. He told me he could tell I was ready physically and mentally. The information this doctor shared with me was invaluable to my recovery. He also said having a strong support person, my wife and son, would be very helpful. September 10, 2021, I entered the hospital to begin the preparation for transplant. Several days of chemotherapy along with total body radiation. The nurse explained I may need help. I would be tired, feel sick. I looked at him with the utmost respect and told him I, on my own, would get up every day, take a shower and get my own breakfast. After breakfast, I will go for a walk with my wife. As it turned out, I was not overly fatigued, I was able to shower daily and take that walk. I never did get sick from the heavy doses of chemotherapy. Now the day is September 16 one day before the transplant. In Judaism this was our day of Atonement. My wife had brought my prayer book. I was told to get up early and eat something before I was to receive the full body radiation treatment. For those reading this, the Day of Atonement is a fast day. No food or water. Of course, this does not apply to people who are ill. This was my first time not fasting and it was on my mind a lot. As I am standing in front of the radiation machine, I started to think about so many things. I closed my eyes and saw my wife and I dancing. I was praying as well. When the radiation was over, I was brought

back to my room and this time I did get sick. First and only time but it was rough. Because it was a holiday, I spent my time praying and visiting with my wife. Because of Covid she was the only visitor allowed other than Clergy. Our Rabbi agreed to come to the hospital on the 17th. Transplant Day. There were two nurses, the Rabbi, and my wife. Unfortunately, the hospital would not let my son be there. That was difficult for us and for him. We prayed while I received the new cells which took about 90 minutes. The Rabbi left and my wife and I walked in the hall and were very anxious. Because my blood levels were so low, I was getting transfusions early in the morning starting the next day. Two days later, I received two more rounds of chemotherapy. Now the waiting began to see if the new cells would take hold. I remember a week going by and nothing registered. Then 10 days and still nothing. On the thirteenth day the nurse came in at 5 am to tell me I had an increase in white blood cells. I remember calling my wife to tell her. We were so excited. Three weeks after transplant, I was able to go home. The transplant doctor we met during the summer explained how important it was for me to get out of bed every day and walk every day while I was in the hospital which I did. Once I got home after being gone a month, things were a little different. For one, I had trouble with stairs and my memory was not that great. I had lost a lot of weight and of course all my hair. Fortunately, I was able to work from the hospital and from home. Focusing on work gave me a much- needed break from focusing on my health. My wife created an environment for me to recover and she was amazing. I tell people all the time I am not certain I would have made it without her. The first 100 days after transplant is the critical time. I made it. I was able to start going back to work the end of December 2021. 2022 came with some challenges. I developed severe graft vs host disease in my mouth along with mucositis and low blood counts. I was hospitalized twice for this. I worked mostly from home during this time. Here we are, January 2023 and I am doing well. The graft vs host in my mouth is finally under control and my blood levels are improving weekly. I have certainly become more spiritual and look at life in a different way. My strength continues to improve, and I can get back to my exercise routine. I am grateful to The MDS Foundation and Be The Match and of course my wife, son and extended family for all their support. This has been and continues to be a journey. I had hope and determination in the beginning and continue to do so. One day at a time. We may not be able to control what happens to us, but we can control how we react. Today is a good day and praying yours is too.

EACH DAY IS A GIFT

BILL STARR

Knoxville, Tennessee

I was diagnosed with MDS in May of 2022. To understand my story, you need to go back a few years to 2014. I retired from a career at General Motors in September 2014. I had spent the previous 14 years in Bowling Green, KY helping to build Corvettes. We had just finished launching the C7 Stingray and it seemed a good time to move onto new challenges. Little did I know what those challenges would prove to be very different than I envisioned. My wife Cindy and I decided to move to Louisville, KY where I would pursue a degree in Biblical Counseling at Southern Seminary. We planned to put that training to use in serving missionaries both here in the States and overseas. So, in September of 2014, we relocated to Louisville and began the next phase of our life.

In the summer of 2015, we rented a house in Santa Rosa Beach, FL and invited our 3 adult children and their families to come spend time together at our 2-week rental. This was our way of celebrating retirement. While we were at the beach enjoying our time together, I noticed that I had a pain in my rib cage on my right side. It was annoying but I didn't think much about it. Once we returned home to Louisville, I had my annual physical and during the visit with my doctor I mentioned the pain in my rib. He felt around and when he hit a particular spot I fell to my knees. Now that hurt! He did an X-ray that day. He read it and was confident it was nothing, but he wanted a radiologist friend to look at it. The radiologist also thought what he saw was likely no big deal, but he suggested a biopsy just to be sure. The biopsy came back, and I was sent to a hematologist for a bone marrow biopsy. That was my first hint that everything might not be all right. On October 5th we met with the doctor, and I was told I had multiple myeloma, an incurable blood cancer. We knew nothing about multiple myeloma and the "Google" search was bleak. I immediately began treatment the week I was diagnosed, and I began to prep for an autologous stem cell transplant which I had in February of 2016.

Cindy and me with our eight grandchildren – a precious memory from our annual beach trip in 2022.

It took about 6 months from start to finish to get back to a "normal" life, but I learned that chemo would be a part of my routine for the rest of my days. I also quickly figured out that fatigue was my new companion. The medicines that were keeping the cancer in check also left me with a compromised immune system. We had to adjust our life rhythms to accommodate this new reality. The upside of this is that when COVID hit, we were already pros at minimizing infection risk!

THE MEDICINES THAT WERE KEEPING THE CANCER IN CHECK ALSO LEFT ME WITH A COMPROMISED IMMUNE SYSTEM. WE HAD TO ADJUST OUR LIFE RHYTHMS TO ACCOMMODATE THIS NEW REALITY. THE UPSIDE OF THIS IS THAT WHEN COVID HIT, WE WERE ALREADY PROS AT MINIMIZING INFECTION RISK!

In November of 2018, I relapsed, and the myeloma returned with a vengeance. We switched our care to the Myeloma Institute in Little Rock, and I had another autologous transplant in March of 2019. It took another 6 months to get back to "normal' and in July of 2019 we moved to Memphis to be closer to my widowed mother and to be closer to our myeloma experts in Little Rock. I was placed on maintenance drugs and the myeloma stayed in strict remission. Thankfully, in the last 10-15 years the drug options for multiple myeloma have exploded. As one drug stopped working, I would switch to another combination. The major side effect from all the medicine was fatigue and that is manageable; annoying but manageable. Many patients have a much more difficult time with side effects than I did. One of the key lessons I learned about Multiple Myeloma (and later MDS) is that my experience is similar to others with the same disease, but it is also unique and specific to me.

Our routine was built around visits to the infusion center, local oncologist check-ups and quarterly returns to Little Rock for MRIs, PET scans, bone marrow biopsies, etc. We had settled into a routine that was predictable and we were enjoying our lives. We planned trips to see family, vacations, etc. around my infusion schedule. Early in 2022, I noticed that my platelet counts were dropping. I was used

to having my blood monitored every month, so there was plenty of data to look at. At the time I was taking one chemo drug and one immunotherapy drug. We stopped each one independently, but the platelets continued to drop. The ANC, WBC, RBC, and hemoglobin were low but they were consistent with previous results. In April I went for my quarterly checkup in Little Rock. This is the first time I ever heard the term MDS. I was told that the next time I returned to the clinic we would test for MDS if my blood numbers continued to deteriorate. We returned to Memphis and during a routine appointment in May, the blood work showed that my numbers were all very low and my ANC was under .5. I was able to get a bone marrow biopsy done that day and it confirmed that I had developed MDS. I stopped all of my myeloma medicines; I started on INQOVI in June and the MDS chapter of my cancer journey began.

Recognizing the real possibility that having two blood cancers likely meant that my lifespan would be shorter, we decided to move to Knoxville where two of our adult daughters and seven of our eight grandchildren live. Ironically Cindy and I have returned to the place where we began our lives together some 45 years ago. I also switched my primary cancer care from Little Rock to Vanderbilt in Nashville as they have an MDS expert in their hematology department. I attended an MDS Foundation

I LIVE IN THE SHADOW OF PSALM 23: *"THE LORD IS MY SHEPHERD; I SHALL NOT WANT."* LIFE IS A GOOD GIFT.

patient forum and participated in an MDSF roundtable with other MDS patients and representatives from Taiho and both were helpful in providing excellent, current information and an opportunity for questions. Yet, even in these forums, I realized that my story is complicated with less treatment options. I have been told that I have therapy induced MDS. It was explained to me that most likely, the years of chemo that I have taken to battle the multiple myeloma have damaged my bone marrow. I have also acquired some genetic changes over these past 8 years that have also affected the function of my bone marrow. I am grateful for my myeloma treatment plan, but in my case, the harshness of the treatment has led to MDS.

Monitoring and managing two blood cancers is difficult as a treatment plan for one can negatively affect the other. Currently the MDS is the focus, and although my myeloma markers are increasing, the growth is slow. I have now completed 6 cycles of INQOVI and am still trying to understand how my body processes the drug. The drug causes wild swings to my blood counts. Looking forward we'll probably consider dosage schedule changes and try to reach an equilibrium with my blood numbers. At this point, I don't have clarity regarding the effectives of INQOVI in my disease management. I have learned that with both multiple myeloma and MDS, getting an answer to the question, "Is it working", is not as simple as one would think. The spoken plan is to have an allogeneic transplant, but we are early in the donor search process. If successful, the transplant will address MDS, but myeloma remains. Without the transplant, I will likely just manage symptoms until they begin to manage me.

I really have no complaints. Cancer has been a teacher in my life, a means by which the Lord has brought me to deeper faith and greater joy. For this I am most grateful. Each day is a gift and I am quick to embrace the time given. It is difficult to live with a chronic condition, one that will likely never not be a part of my life. At the infusion center, you often hear a bell rung when a person finishes their chemo. I will not ever "ring the bell" as my treatment, in some form, will last as long as I do. I don't see that as a sad thing; it is my reality.

GET BUSY LIVING!

JOAN POWELL

Laguna Niguel, California

In 2014, Joan was busy handing out candy to the tiny ghouls and goblins of her neighborhood, but the scariest thing that Halloween was a phone call.

It was her doctor, who told her to take a break from trick-or-treaters and sit down for what came next. As Joan's heart began to pound, her doctor delivered the diagnosis. Joan had myelodysplastic syndromes — or MDS — a rare blood disorder that is considered a type of cancer.

Joan recalled: "The doctor said, 'Get a piece of paper and write it down.' And she spelled it. She must have had to spell it like three or four times because I just...I was so nervous."

At 9 years post-diagnosis, Joan is a powerhouse when it comes to advocating for her condition, treatment, and the advancement of its scientific research. She's traveled, in her words, "from the beaches of California to the Capitol steps," as an advocate for patients with MDS. Since 2015, Joan has been a Patient Advocate and member of the MDS Foundation, and now the group leader for the MDS Foundation's Southern California Support Group. She credits this phenomenal organization for supporting her with her roller coaster MDS journey from the beaches of California to the Washington Capitol Steps.

An important part of Joan's advocacy is explaining myelodysplastic syndromes as a group of bone marrow disorders. (That is why "syndromes" is plural, she says). Broadly speakin Joan explains, MDS is when stem cells in bone marrow stop functioning, preventing the blood cells from properly forming or working.

It has not always been easy for Joan to adapt to the realities of her condition. Her treatment involves frequent blood transfusions, self-administered injections, and expensive medication.

Joan, who was already retired and on Medicare at the time of her diagnosis, estimated that her annual out-of-pocket costs are upwards of $100,000 throughout the years of treatment.

The assistance of financial support from several Patient Assistance programs have been a life saver.

"I must admit, I was very depressed," she said, recalling her early days, post-diagnosis. "The stress of not knowing how you're going to pay your co-pay is a nightmare, because most people with chronic illnesses are already in a stressful situation." To stay motivated, Joan adopted a motto — "get busy living"— borrowed from The Shawshank Redemption. It is a maxim she embodies to the fullest. Between visits to the doctor and hospital, Joan's schedule is filled with community service and advocacy — even as activity has shifted to online formats during the pandemic.

Joan serves as the president of the National Council of Negro Women in Orange County; and is an active member of the Delta Sigma Theta Sorority, Inc, (a non-profit organization for sisterhood, service, and scholarship organization. She is an officially appointed California delegate for a political party; and volunteers to encourage civic engagement at the state and national level. And, of course, Joan is a passionate advocate for patient's health care rights and with numerus patient and MDS organizations.

She believes her role as a patient advocate is especially important as an African American woman, since African Americans are underrepresented at advocacy events. Above all, she wants others to know they aren't suffering alone — that she is with them.

More than anything, Joan does not dwell on her diagnosis. She makes the most of her time by speaking up for patients like herself, learning about the latest research and treatment options for MDS, and surrounding herself with positive people. It is her mission to have a better quality of life.

Or, in Joan's words: "I took those lemons and made lemonade."

Joan has traveled "from the beaches of California to the Capitol steps," as an advocate for patients with MDS.

A 10-YEAR JOURNEY

OWEN MAGUIRE

High River, Alberta, Canada

I am 84 years of age and grew up in Eastern Canada Toronto and the majority of time in Ottawa, Canada's Capital. In 1958, I engaged in the Royal Canadian Mounted Police and served 33 years in postings across Canada and retired with the Rank of Superintendent. I then took a 5-year contract with the Saskatoon Police Commission in the Province of Saskatchewan as Chief of Police in the City of 250,000. My wife was an RN who spent 30 years in the OR or Hospital Emergency Department, depending on what was available as we moved 12 times for my job. In 1996, we retired in High River Alberta beside a golf course just south of Calgary and spent the winter in California intending to buy winter property. Unfortunately, both of us realized we needed more brain stimulation and could only play so much golf. When we returned home, I was appointed to the Alberta Transportation Safety Board and served 14 years and was appointed to the Alberta Mental Health Review Panel for 12 years. For 15 years, we travelled to Oxnard, CA for 6 weeks during February and March with a group of other Canadians and Americans to play golf. Life was good.

In October 2012, I had my annual medical in the afternoon after working out at a fitness centre and then playing 18 holes of golf that morning. Five days later, I was summoned to my doctor's office and advised that I had A Fib

and that my hemoglobin, WBC, and platelets were all below normal. A week later, I was having a bone marrow biopsy done, and three weeks later my Oncologist gave me the news that I had MDS. He was what could best be described as gruff old school and had been recognized as a leader in the Bone Marrow field but was blunt and to the point. There was no sugar coating and that suited me just fine. I was placed on watch and wait and continued on much as I had in the past.

In May of 2013, I had surgery and my Oncologist advised he had provided information to the surgeon on my condition. When I was being prepped for surgery, the anesthesiologist told me that the surgeon was reluctant to prescribe antibiotics prior to surgery and I never found out what the outcome was. A week after returning home from the hospital, I became quite Ill and went to an Urgent Care Clinic. I had an infection from the surgery and was placed on antibiotics and sent home. Two days later, the river that runs through our town of 1,400 overflowed its banks and much of the community including our Regional Hospital was flooded. Our residence was spared but we were forced to evacuate. We drove to Calgary and stayed in a hotel for a week, but my medical condition did not improve. We were finally allowed to return home and two days later I was in my family doctor's office and passed out. I was taken to the hospital and diagnosed with dehydration and Clostridioides difficile to go with the continued infection.

I do not remember much about the first few days as the main concern was dealing with the C. defficile. I vividly remember the doctor meeting with my wife and daughter, who had flown from Vancouver, at my bedside and saying without a blood transfusion he feared I would not survive. Later that day, I received two transfusions. My daughter describes what happened next as a miracle. Within two days, I was able to get out of bed by myself and by the end of the week I was walking the hospital halls unaided.

It took about three months before I was able to regain my full strength and do all my usual routine including golfing. I have never had to have further blood transfusions. Things were going well until 2015, when my hemoglobin took a dive, and I was placed on Epoetin Alfa (Eprex) after I confirmed that my private drug plan would pay 80% of the $2000.00 bill for the drug each month. My hemoglobin stabilized but was still around 12. I was still playing golf and exercising.

In January 2016, I had another bone marrow biopsy and the blasts had risen to 6% from 4% when I was diagnosed. I started Vidaza in April 2017 and have been on the drug ever since. A further bm biopsy in May 2018 showed 3% blasts. In June 2018, my Oncologist retired, and I was referred to an Oncologist who is on the Transplant Team at the Tom Baker Cancer Hospital in Calgary. She is progressive and has tweaked my drug program to some extent.

1970, when I was part of the Prime Minister of Canada's Protection Detail (similar to USA Secret Service). I am in white trench coat. Prime Minister Pierre Trudeau is 1st person in front on right and behind him is the Premier of Quebec, Robert Bourassa.

In the spring of 2022, I began having shortness of breath while taking my 3km walk, and initially thought my hemoglobin had taken a dive. This proved false and an echocardiogram was done. The result was I had a semi plugged aortic heart valve. The Specialist said a TAVI (valve replacement) should be done but would liaise with my oncologist before a decision was made.

The rest of my information comes from my oncologist who advised me she was asked how long I was expected to live. (No sense wasting a valve on someone who would die shortly). My oncologist did a workup on me, and she advised him that her projection was 5 years. In the meantime, my wife who was in a care home with dementia had digressed to the point where she had to be moved to a long-term care facility and my daughter flew here to assist me with the transfer. She brought 2 work laptops with her and was going to stay a week. She stayed a month.

The day after we moved, my wife and I came down with Covid. My oncologist prescribed Paxlovid which was fortunate as despite having 4 doses of the vaccine, my daughter tells me I was so sick that I did not know where I was. On the 3rd day, the Paxlovid kicked in and by the 6th day I was testing negative. 2 days later the phone rang, and I was advised I was booked in 2 weeks' time for the heart valve replacement. Once again consultation between the heart specialist and oncologist took place because of COVID. The operation consisted of inserting a catheter in an artery in the groin with the new valve and working it up to the defective valve and shoving it inside, overnight in hospital and then home. Thank goodness for my daughter being with me as I was restricted for 2 weeks. No aftereffects and my blood readings have returned to where they were before the operation. I am still trilineage but other than endurance and fatigue with a sore stomach from the needles at the end of each cycle, I lead a normal life. I finished my 77th 7-day cycle of Vidaza yesterday and am being held up as somewhat of a poster boy.

High River Cancer Clinic. It is Halloween and all the nurses, doctors and Tilly the Rescue Dog are dressed in costume, and I am getting ready for my 2 needles. Tilly was rescued as a 3-month-old pup from Mexico by Becky, one of my chemo nurses. She greets everyone at the entrance and seems to know who really needs support. She does have a great affinity for a warm blanket and people who bring cooked bacon for her.

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, Suite 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.

UNDERSTANDING A COMPLETE BLOOD COUNT (CBC)

CATHERINE MICALES
McDonald, Pennsylvania

My name is Catherine Micales and along with being a patient with MDS, I also am a Medical Technologist with a specialty in Hematology. It's my belief that knowledge is power and with that; as a patient and a medical professional understanding our laboratory results in particular; those that are used to follow disease can be of value. Especially, in a disease where we ourselves have very little control and at times, even less understanding of what the 'numbers' actually mean.

With that, I wanted to provide a reference for patients and caregivers to explain what a Complete Blood Count (CBC) is, especially in diseases that involve the bone marrow, and why this 'test' is critical to the doctors in the management of this disease.

My hope, is that this helps shed some light on understanding the importance of this test.

Wishing all of my fellow warriors all the best in your journey!

A CBC is a blood test used to evaluate your basic health and detect a range of disorders (such as anemia, infection, etc). A CBC evaluates each type of cell in your blood (which we will discuss below).

Sometimes, the CBC will include what is referred to as a Differential (DIFF for short). The differential is a count done on the white blood cells (that is performed either automatically by the instrument or manually by a Medical Technologist, Pathologist, etc).

A CBC FROM PERIPHERAL BLOOD CAN PROVIDE US WITH SOME INSIGHT AS TO WHAT IS GOING ON IN OUR BONE MARROW.

The DIFF literally differentiates the different white blood cell types from one another and can be used again, to evaluate overall health, detect a range of disorders, especially in MDS and some of the other blood cancers (eg., Leukemia, Multiple Myeloma, etc).

The CBC uses what is called peripheral blood (that is blood, which is drawn from a vein in your arm or hand). As the cells of the blood (specifically White Blood Cells, Red Blood Cells and Platelets) are born and produced by the stem cells in the bone marrow; a CBC from peripheral blood can provide us with some insight as to what is going on in our bone marrow.

The CBC itself has two distinct parts. The first part has several parameters that are measured:

WBC (white blood cells): responsible for responding to infections, allergens, etc.

RBC (red blood cells): responsible for carrying oxygen throughout the body and CO2 back to the lungs.

Hgb (hemoglobin): measures the amount of hemoglobin in the red blood cell. Iron is a major component of hemoglobin and is what oxygen binds to.

Hct (hematocrit): measures the proportion of red blood cells in your blood.

Platelet count: measures the number of platelets in the blood. Platelets are responsible for blood clotting

***MCV (Mean Corpuscular Volume)}**

***MCH (Mean Corpuscular Hemoglobin)**

***MCHC (Mean Corpuscular Hemoglobin Content)**

***RDW (Red cell Distribution Width)**

***MPV (Mean Platelet Volume)**

MCV, MCH, MCHC, RDW and MPV are called indices and these parameters relate to the mean (average) size of red blood cells, how much hemoglobin the cell contains and the size of the red blood cells (width). Together the indices along with the RBC, hemoglobin, and hematocrit, are helpful to further evaluate certain types of anemias or B_{12} folate deficiencies.

MPV measures the mean platelet size/volume and is helpful in determining the size of the platelets being produced by the marrow.

The Differential (DIFF) as mentioned is the 2nd part of the CBC, counts or differentiates the different type of WBCs in the blood. There are a total of five (5) different types of WBCs, each with a different role in the body (eg., Neutrophils are responsible for attacking bacteria, Eosinophils release histamine and are elevated during allergies). The different types of WBCs are:

Neutrophils

Lymphocytes

Monocytes

Basophils

Eosinophils

You may also see the WBC diff represented as relative percentages (%) or in absolutes. Relative percentages count 100 WBCs and the number of each type of cell counted is then represented as a percentage (eg., 70% neutrophils). Absolute counts are done by the instrument and count a far greater number of cells and maybe reported as smaller numbers compared to the percentage (for instance, 70% neutrophils v 5.0 k/mcL).

FOR THE MDS PATIENT YOUR PHYSICIAN WILL BE LOOKING AT THE CBC RESULTS TO DETERMINE:

If there is a need for a blood transfusion? The key element that would determine this is the Hgb result. If for instance, your

hemoglobin is below a specified criteria then, your physician will advise that you need to come to the transfusion center or hospital to receive a blood transfusion. The intent of blood transfusions is to increase your hemoglobin level (as with lower hemoglobin levels: symptoms such as fatigue, shortness of breath, dizziness,) are often experienced.

Another determinant is the a need for a platelet transfusion? Similarly, if your platelets are below the established parameter that your doctor or institution follows, you will be called to come in to receive a platelet transfusion. Platelets are important as they play a role in blood clotting. If your platelets are critically low, the risk of bleeding is significantly increased.

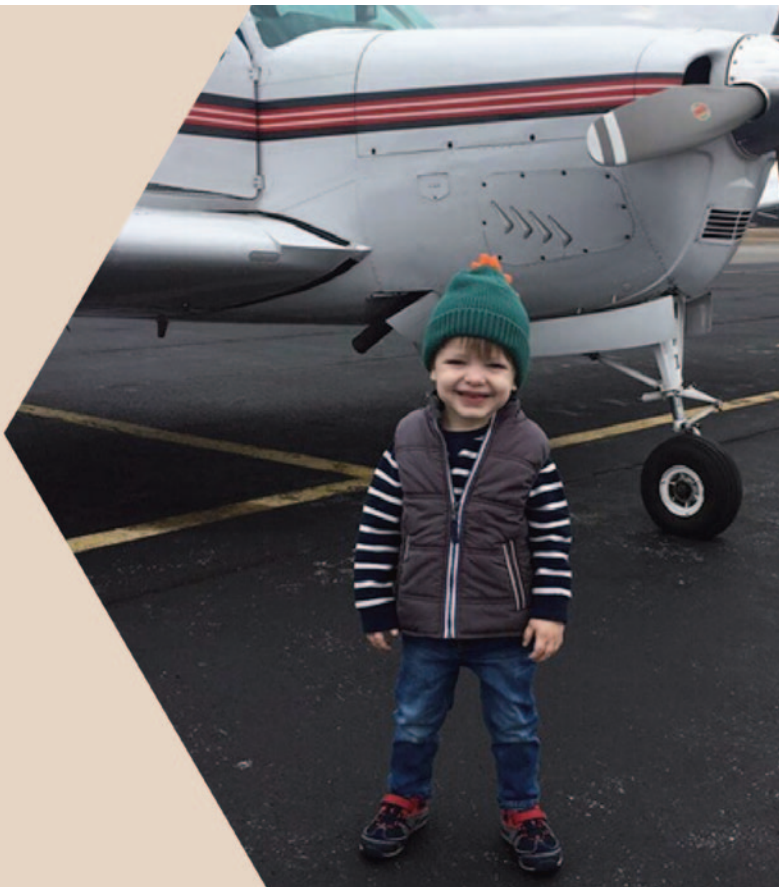
The other parameter that is important for MDS patients – especially those receiving chemotherapy and/or conditioning therapy for SCT or undergoing or recovering from SCT, is the Absolute Neutrophil Count or ANC.

This is a term that many of us are familiar with and it is an important parameter. ANC is a derived number meaning, it is calculated using the (neutrophils% + segmented bands%) x the total WBC count x 10. ANC is a critical measure of neutropenia which again, for patients undergoing chemotherapy; neutropenia (defined as ANC less than 2.0) represents a need to be cautious.

When the ANC is low, your physician may place you on a bone marrow stimulant (eg, neupogen) to literally promote more white blood cell (neutrophil) production in the marrow. When ANCs are dangerously low, patients are also at risk of what is known as neutropenic fever. Neutropenic fever is considered an oncologic emergency. Anytime, you have a dangerously low ANC (less than 0.5) coupled with a fever greater than 100.4°F it is imperative that you contact your physician immediately.

Another white blood cell that you may see on your lab reports is a cell that is known as a "Blast". A blast is actually an immature version of the (adult) neutrophil. The RBCs, WBCs and Platelets are born in the bone marrow and in a healthy marrow once these cells have gone through their maturation or evolution; they are then released into the peripheral blood streamIn diseases such as MDS, and especially AML, the marrow becomes too crowded with cells and begins to release cells prematurely into the peripheral blood.

In MDS; blasts also are part of the IPSS-R (International Prognostic Scoring System – Revised) scoring system. They are generally seen on a slide from your CBC (peripheral smear) rather than counted by the instrument as with the diff. Additionally, blasts are also present in the bone marrow and can be counted/noted by the reviewing pathologist when reviewing slides of bone marrow aspirate following a bone marrow biopsy.



AML CORNER

AML RESOURCES

YOU AND AML:
AN ANIMATED PATIENT'S GUIDE TO ACUTE MYELOID LEUKEMIA

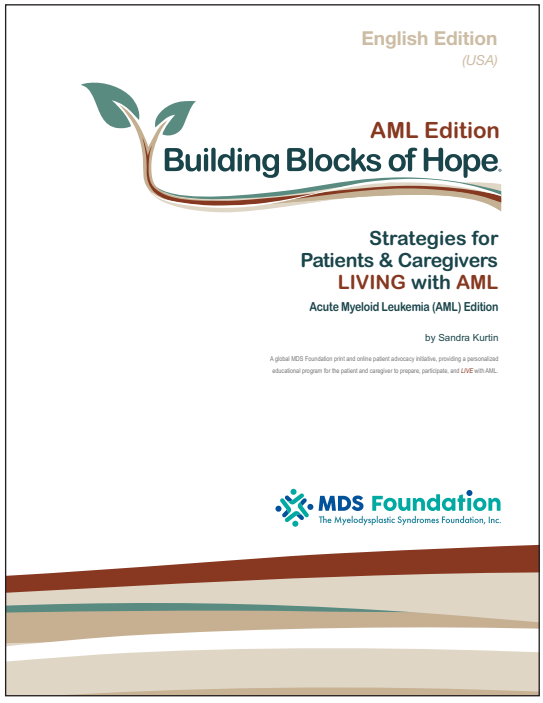
This resource is intended for patients with acute myeloid leukemia (AML). You will find expert advice about AML, AML with myelodysplasia-related changes (AML-MRC) and treatment-related AML (tAML) to help you discuss key issues with your healthcare provider and make important decisions related to management and treatment.

"YOU AND AML" CONTAINS 4 LEARNING MODULES:

- Understanding AML
- Understanding AML-MRC and tAML
- Diagnosing AML, AML-MRC and tAML
- Treatment of AML

"YOU AND AML" – NEW MODULES AVAILABLE!

- Maintenance and Continuous Treatment in Acute Myeloid Leukemia
- Treatment Failure and Relapse in Acute Myeloid Leukemia



BUILDING BLOCKS OF HOPE

You or someone you know has been diagnosed with AML.

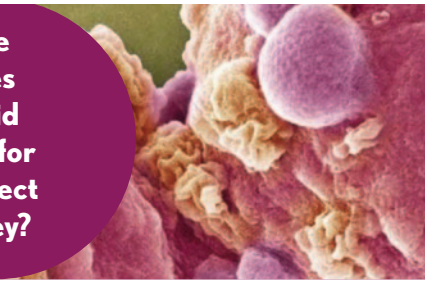
Hearing the words Acute Myeloid Leukemia or AML can be frightening. The diagnosis of AML is often unexpected and filled with both immediate and long-term challenges. You probably have many questions. Allow yourself time to adjust to the diagnosis of AML. Take time to explore the Building Blocks of Hope®, it is designed to help get you the information that you are looking for and take an active part in your AML journey. This is a great way to share this information with family and friends. The AML BBoH contains four chapters and a glossary of terms:

Chapter 1: Understanding Acute Myeloid Leukemia
Chapter 2: Seeking Treatment
Chapter 3: General Resources for Living with AML
Chapter 4: The MDS Foundation

FIND THE RIGHT FIT

Navigating Secondary Acute Myeloid Leukemia

Do you or a loved one have myelodysplastic syndromes or secondary acute myeloid leukemia and are looking for resources or ways to connect with others on your journey?



People affected by myelodysplastic syndromes (MDS) or secondary acute myeloid leukemia (sAML) often face many uncertainties on how these diseases develop and progress, what available treatment options there are and the impact they may have on everyday life.

For those in search of answers, Find the Right Fit can provide information and educational resources for people living with MDS or sAML, as well as their loved ones who often take on the role of caregiver.

A cancer diagnosis can be overwhelming, but **knowledge is power**. To help navigate each person's individual journey, Find the Right Fit **provides a collection of tools** including articles, videos, patient stories and more that:

Educate on the science behind MDS and sAML

Offer information regarding treatment options and coping strategies

Connect patients and their loved ones with the appropriate resources to manage an MDS or sAML diagnosis with confidence

Visit FindTheRightFit-sAML.com.

About AML

- AML is an aggressive (fast-growing) disease in which too many myeloblasts (immature white blood cells) are found in the bone marrow and blood.[1,2] sAML is one type of AML that may be linked to specific preexisting conditions, like MDS, or to prior treatment for a malignant or non-malignant disease.[3]

Visit FindTheRightFit-sAML.com to learn more about sAML subtypes and treatment options.

About MDS

- MDS, a form of blood cancer, are an often unrecognized, under-diagnosed, rare group of bone marrow failure disorders where the body can no longer make enough healthy, normal blood cells in the bone marrow.[4]

- The cause of MDS is unknown, but potential triggers include radiation and chemotherapy for cancer, as well as long-term exposure to certain environmental or industrial chemicals, such as benzene.[4]

Visit FindTheRightFit-sAML.com to learn how MDS can progress to sAML.

Find the Right Fit is a program from **Jazz Pharmaceuticals,** developed with consultation from the **Myelodysplastic Syndromes Foundation, Inc.** and the **Cancer Support Community.**

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Jazz Pharmaceuticals

Know AML is the first global AML awareness and education initiative. Our goal is to facilitate and improve AML knowledge worldwide and develop community-based initiatives to overcome current and future challenges.

know-aml.com

MY JOE & JOSHUA

KATHERINE HOURT
Mesa, Arizona

I reached out to the MDS Foundation to find out about raising awareness. I left a brief message about the loss of my husband and son to the illness. I then received a phone call from Audrey Hassan and was invited to share their stories, so I will to the best of my recollection. Lest I forget, "Thank You" to Joe & Josh's wonderful hematologist/oncologist and his wonderful team!

Joe's journey started around 2009 with low counts on his lab reports. It wasn't until early 2010 that the Hematologist ordered a bone marrow biopsy, and that is when I got involved. We received the results in April of 2010. The doctor said he had myelodysplastic syndrome! The first thing out of my mouth was "Myelo- what?!" His genetic testing had shown some chromosome involvement, so his diagnosis was del 5q MDS associated with refractory anemia. It was at that time I started researching everything I could to learn about this disease. I also researched all of his lab reports. He also was DMII (diabetic type 2) and on insulin. Joe was given an oral chemo to start, and continued this form of chemo for several months. He was becoming more and more fatigued, and was violently ill every day. He could still drive the first year, however that changed in 2011. His counts started dropping even more, and he needed blood. The doctor spoke of having a port-a-cath placed to receive his future treatments, so we did that. I recommend always having one placed. He also had been prone to ear infections throughout his life, and had developed one that year that put him in the hospital for four days! Now, he was neutropenic, and the infection spread like wildfire! He was in so much pain! It was hard because I could not do anything to help him – I could only be there for him. He did have another infection under his armpit, and this one was a mystery. It took four visits to finally figure out how he was getting reinfected. When he took a shower, he washed himself

from head to toe, and then back up, and this was bringing bacteria to his armpit. So, lesson learned! Always wash from head to toe, and never back up. His need for blood continued to increase, and we would go every week to the OTC (Out Patient Treatment Center) at the local hospital. His MDS was very aggressive and the doctor ordered another bone marrow biopsy. We received the results on December 23, the day before Joe's 51st birthday. I remember it well, it was a Friday.... the diagnosis was AML. We were allowed to have the weekend to enjoy Christmas together as a family, before Joe would be admitted to the local hospital for a long stay. He would receive two forms of chemo and a steroid for 7 days (one chemo was stopped after 3 days), around the clock to try and put the AML in remission. It was not easy, and he put on 60 pounds of fluid which they removed with lasix. He started to lose his hair. He became vanko resistant and his body started to shut down, his lungs filling with fluids. At that point the ER doctor said he would be going to the ICU. I was quite overwhelmed at this point, and knew the end was near. That was Sunday, January 15, 2012. On Monday, while I was visiting, I was afraid to sit close to him because he was sedated and the tubes bothered me. But, I will tell you, that he knew I was there and he fought to turn and twist his head around to look right at me through squinted eyes. A single tear dropped onto his cheek. I said to him, "You are saying goodbye to me, aren't you?" They are always aware even under sedation. He was gone the very next day, Tuesday, January 17. We have always been very religious, and I have a very strong testimony of a loving Heavenly Father! Joe was shown sweet tender mercies throughout his illness. Once (in 2011) he was helping the young priests at church by driving them around to the homes of those members who were not able to come to church and partake of the sacrament. He returned to the church building, where I was waiting, and he did not look good. I ran to the Stake Office and quickly returned with two brethren, and we took Joe into their office. They administered a priesthood blessing to him and he regained his strength and his pain was taken away. He was not healed, but he did receive a sweet tender mercy from the Lord! One more quick note about Joe, he was a veteran of the United States Air force, and also served in Operation Desert Storm, Saudi Arabia (he worked w/nukes).

Next, I would like to tell you about our son, Joshua. His health had started to decline in his teens. Josh had a head injury during a scouting event, and six months later developed an essential tremor, which affected him the rest of his life. In 2018 he passed a kidney stone, and while we were in the ER, the doctor told us his blood sugar was over 300! Welcome to the club! He was diagnosed with DMII (just like his dad), and returned two days later – only to be admitted with a blood sugar level around 500. Some time after that, Josh started to lose weight, and lost almost 75 lbs. We found out that he had pancreatitis, and his pancreas was not functioning normally. He needed a special medication, which he took with every meal and snacks to help breakdown his food to get the nutrients he needed. Josh became totally dependent upon me. So, not a good start! It was then we first found out his platelets were low, and went to see a hematologist (same doctor my husband saw). The platelets were ok for a while. It started up again in 2020. In early 2021 the doctor ordered a bone marrow biopsy. To our surprise (or not!), Josh received an MDS

diagnosis. The genetic testing did not show any chromosome involvement, so slightly different than Joe's diagnosis. Josh continued to have kidney stones, and even had a surgery to have one removed. His platelets continued to decline rapidly, and he had a port placement in his left chest. He needed this for chemo, and for platelets. He soon developed clots and an infection in the surgery site, so the port had to be removed. Josh had his first chemo in September, and was soon admitted to the hospital with complications. He struggled and had such a difficult time in the hospital. He then decided to try again with a new port placement (right chest). Well, he developed clots again, and there was some blood accumulating under the surgery site – but, not infected, so the port stayed. Thank goodness! Josh did have a second round of chemo in October. It was hard for him, and there was even a stem cell transplant in the works for November. It was then that I decided to have a talk with him to be sure how he wanted to proceed. I felt he was struggling too much. He said "No more chemo", and he did not want the stem cell transplant. Josh's life was not the best situation. He spent his days on his laptop, in his room, getting treatment, or in doctor's offices. His quality of life was not good, so he did not wish to prolong it any further. He did, however, agree to keep receiving platelets. Through the new year, he seemed to remain stable, and in April 2022, he started a fast decline. It was very aggressive. The doctor had given a prognosis of 3-6 months. Josh had started feeling some discomfort in his chest, and developed lumps of blood over his body. He had pain everyday, usually in his shoulders, or neck, or back. His platelets were critical, and he was admitted to the hospital on August 6th, needing a transfusion. I had been helping him shower and dress every day. It was taking it's toll on me, but I loved my son, so I pushed myself to continue caring for him as long as he needed me to. At that point, his body had started to shut down. He didn't eat much, or talk very well, his throat was swollen. The discomfort in his chest turned out to be fluid on his right lung. He was receiving

I NEED TO MENTION HOW STRONG JOSH WAS THROUGHOUT THIS JOURNEY. HE ENDURED IT WELL. HE WAS MY "JOY", AND HE HAD SUCH A SWEET SPIRIT. I COULD NOT HAVE ASKED FOR A BETTER SON!

platelets and blood until August 8th. The next morning when I arrived at the hospital, the ER doctor informed me that Josh's body would no longer accept any product, blood or platelets, and they wanted to place him on hospice. I agreed, all treatment was stopped, and he only received comfort care (which included his propanolol for tremors). He could no longer eat, and was given pain meds for his UTI. He was bleeding since his admission on the 6th. When someone has low platelets, you can not sedate or intubate them, it would cause too much trauma to their throat, so hospice was the only choice we had. He was also on oxygen – and I will explain why I'm telling you this. It was decided that on the 10th Josh would be transferred to a hospice facility so they could give him better care. The next day a driver arrived at 5 pm to take Josh to the facility, so I thought I would help by removing his oxygen. Big mistake. I was totally unprepared for what happened next. His oxygen level dropped to 57%, and he became combative. He looked "wildeyed", and started calling for help. He swung his arms out and got me with a right hook and then a left! It was soft, it didn't hurt me. They had to get his oxygen back on quickly and give him some relaxation meds. I ran out into the hallway area, and the driver ran over to me, put his hands on my shoulders and told me it would be ok. I was so devastated! We finally got him in the vehicle, but I wasn't sure he would make it to the facility. He did. We got him inside, they took him back and cleaned him up, and then I was allowed to go back with him. He was still combative because of low oxygen, and would reach out and pinch me, or poke me, and try to get up and leave! He was strong for being so ill! The hardest thing I've ever done in my life was to watch the life drain from my son's body. By 10:30 that night Josh was gone. He was only there for five hours,... so fast! I had prayed to heavenly father, please just take him. I need to mention how strong Josh was throughout this journey. He endured it well. He was my "joy", and he had such a sweet spirit. I could not have asked for a better son! I had known for several years that I would bury my son. I had a dream... my savior always prepared me for hard things in my life. I thank God everyday that I was given the opportunity to be his mother. Joe had felt for several years that he would not have a long life. I think his family history may have played a part.....

Please love them while they are here! No matter how we treat one another in this life, when they're gone, that all changes!

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Patients and caregivers:
Survey participation request

Do you suffer from, or care for someone fighting Myelodysplastic Syndrome (MDS)?

The MDS Foundation is assisting in the recruitment of people with MDS and caregivers of people with MDS for an online survey. Cerner Enviza, an independent, third-party research organization, is conducting the online survey on behalf of the study sponsor, a pharmaceutical company, and we kindly are asking for your help.

The primary objective of this study is to learn more about the experiences of people with MDS. We would like to understand how people with MDS manage and choose drug therapies to treat their MDS, and how caregivers of people with MDS are affected.

In order to qualify, participants must meet the following criteria:

- Diagnosis of Low Risk MDS
- Received at least 2 red blood cell (RBC) transfusion events in the past 4 months
- Age 18 or older
- Caregiver participants:
  - Must be a primary or co-primary caregiver

Understanding your experience and having your voice is critical to ongoing research in MDS and we would be grateful for your participation.

If you have any questions about this survey, please contact MDS_PreferenceStudy@cernerenviza.com

Survey available April 2023:
The survey will be sent via email from the MDSF

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