



MDS Foundation

The Myelodysplastic Syndromes Foundation, Inc.

NEWSLETTER

The Myelodysplastic Syndromes Foundation, Inc.



VOLUME 31 ISSUE 1
SPRING/SUMMER 2025



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Peggy Ann Torney
The MDS Foundation



Dear MDS Community,

At the beginning of this year, I had the profound honor of joining the MDS Foundation as Chief Executive Officer. I embrace this role with deep gratitude for and unwavering commitment to serving our extraordinary community of patients, caregivers, healthcare professionals, and partners. Together, I know that we will build upon the strong foundation you have helped to create, advancing our mission with passion, purpose, and an unrelenting focus on progress.

At the heart of the MDS Foundation is our mission to provide support, education, and hope to those affected by myelodysplastic syndromes (MDS).

Since stepping into this role, I have been inspired by the resilience, courage, and dedication of the MDS community. While this may not be a community you chose to be a part of, I hope that you feel supported and hopeful now that you are here with us. Whether you are navigating a new diagnosis, supporting a loved one, or providing care – the MDS Foundation is here to support you every step of the way.

We are at a pivotal moment in advancing care for MDS. Groundbreaking research and emerging therapies are offering new possibilities, bringing more hope to our community than ever before. The MDS Foundation is committed to accelerating this momentum—working alongside healthcare professionals, researchers, and industry leaders to drive innovation, improve patient outcomes, and ensure equitable access to the latest treatments and disease information. Central to this work is our unwavering priority to empower every patient with the knowledge, resources, and support needed to make the best decisions for their treatment and long-term care.

Beyond advancing research and treatment, we are expanding our efforts to strengthen resources, foster meaningful connections, advocate for those impacted by MDS, and amplify the voices of our community. Your insights and experiences are essential in shaping the future of the Foundation, and I encourage you to share them with us so we can continue to meet your evolving needs.

I am honored to work alongside each of you to advance our vital shared mission. I genuinely believe the future is one of progress, purpose, and—above all—hope. Together, we will deepen our impact, drive meaningful change, and create a brighter future for all those affected by MDS.

A handwritten signature in black ink that reads "Peggy Ann Torney".

Peggy Ann Torney

Chief Executive Officer
MDS Foundation



Move FOR MDS
Community Walks to Drive Awareness
& Accelerate Research

JOIN THE MOVEMENT AND MOVE FOR MDS IN 2025

Join a family-friendly 5K and walk, run or wheel to raise critical funds for MDS. You can spread awareness, inspire hope, and move MDS research ahead simply by taking a walk.

Event Information:

TAMPA / Al Lopez Park
April 27

CHICAGO / Burnham Park
May 18

NEW YORK CITY / Battery Park
September 14

BOSTON / Boston Common
October 19

REGISTER HERE



LEARN MORE or REGISTER at www.moveformds.org.

Spend the day supporting those impacted by myelodysplastic syndromes (MDS) while enjoying yard games, face painting, caricature artist, photo booth and more.

This isn't just a walk- it's a movement of hope and progress. Bring your friends and family, and let's take meaningful steps for MDS together!



FROM THE FOUNDATION



Your Life. Your Treatment. Your Way.

Personalized Clinical Trial Support

The MDS Foundation is committed to helping you understand all of your treatment options. That's why we've teamed up with Spark**Cures** to develop a clinical trial matching portal that delivers personalized results for MDS clinical trials and centers.

We understand that finding the right treatment option is an ongoing process, and as part of our commitment, we regularly check in with patients to ensure they're aware of trial options throughout their journey, including precursor conditions like CHIP, CCUS, and ICUS.

KEY BENEFITS:

- Find MDS Centers of Excellence near you or anywhere across the US.
- Discover trials that treat MDS or that treat your symptoms - such as anemia.
- Easily stay on top of your clinical trial options with personalized results that are constantly updated.

Get started today by answering a few questions.

Or if you'd prefer, you can call SparkCures directly and we can help get you started.

(888) 803-1766.

<https://sparkcures.com/mds-start>



ABOUT US

We are a global non-profit advocacy organization building critical awareness of myelodysplastic syndromes (MDS) - a rare, often undetected blood cancer. The MDS Foundation was the first non-profit 100% dedicated to myelodysplastic syndromes (MDS). The MDS Foundation has supported patients and their families, as well as healthcare providers, in the fields of MDS, AML and other related cancers for over 30 years.

Vision

We envision a world where every MDS patient has access to the best possible care, treatments, and support—driving advancements in research, increasing awareness, and ultimately improving outcomes for all those impacted by MDS.

Mission

The MDS Foundation is dedicated to improving the lives of those affected by myelodysplastic syndromes (MDS) through patient support, professional education, research, and advocacy. We strive to empower patients, caregivers, and healthcare professionals with the knowledge and resources needed to navigate MDS with confidence.

Patient Support & Advocacy

Patient Forums & Webinars



Live forums globally and virtual webinars with up-to-date information on MDS

Support Groups



Global support groups both live and virtually

Clinical Support



Our on-staff nurse helps answer your questions, offer direction, and assist with referrals to *Centers of Excellence* for care

Treatment & Clinical Trial Information



Up-to-date information on available treatment options and clinical trials

Educational Materials



We offer MDS educational resources in over 20 different languages

Interactive Tools & Platforms



We provide learning platforms, educational tools, and community message boards



Professional Education & Resources

International Congresses & Symposia



Annual global MDS educational meetings for healthcare professionals.

Clinical Trial Portal



Professional clinical trial matching tool

Research and Development



We drive cutting-edge MDS research through our Young Investigator Grant Program

Prognostic Tools



IPSS-M & IPSS-R prognosis calculators

Professional Membership



A community of healthcare professionals dedicated to scientific advancement and treatment of MDS

Centers of Excellence



A global referral network of centers that excel in MDS treatment and patient care

CME Credited Courses



Continuing education credits available through MDS Foundation events

Educational Materials



We offer MDS educational resources in over 20 different languages

CONTACT US



patientliaison@mds-foundation.org
hcp@mds-foundation.org



U.S. calls [1-\(800\)-637-0839](tel:1-800-637-0839)
Global calls [1-\(609\)-298-1035](tel:1-609-298-1035)



www.mds-foundation.org

Learn More





Do you know...

Do You Know Your MDS Subtype, IPSS-M Score & Gene Mutation Profile?

MDS treatment is individualized based on a patient's subtype, IPSS-M score and, to some extent, genetic mutations. 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-M score are determined, as well as general information on genetic mutations commonly found in MDS and the importance of genetic testing for these mutations.

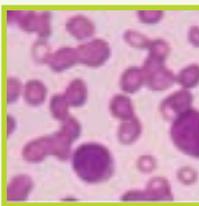
Knowing your subtype, IPSS-M score and gene mutation profile will help facilitate discussions with your healthcare provider on what this means for you personally and help select the best treatment options.

IPSS-M Score

The IPSS-M 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.



Bone Marrow Blast



MDS-RS-MLD



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.

Visit Our Microsite

Understanding Your MDS: Know Your Score, Your Subtype, And Your Mutation

This publication 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

To learn more, visit our website at www.mdsknowledgeispower.com

To order your free copy of **UNDERSTANDING YOUR MDS: Know your Score, your Subtype, and your Mutation**, please call 1-609-298-1035 or scan the QR code.



To learn more, visit our website at <https://www.mdsknowledgeispower.com/>.

PATIENT STORY



Gary A. Miller, PhD
New Jersey

I'm Still Me

In 2021, Gary was diagnosed with prostate cancer. Routine bloodwork indicated his blood counts were low, which led him to a hematology consult. Two weeks later, he received a diagnosis of myelodysplastic syndromes (MDS). While his prostate cancer was treated with no complications, his MDS proved to be a longer journey for Gary.

“I received a bone marrow transplant (BMT) nearly three and a half years ago. The procedure went smoothly and there were no immediate significant complications. However, post transplant recovery has been long and challenging.”

You can read more about Gary’s story and personal experience by scanning the QR code.



Gary hopes **“the article resonates with my fellow cancer companions and provides something of worth; even better if a non-cancer person gains awareness of how their thinking and actions are received.”**

And most importantly:

“A cancer diagnosis is not a terminal sentence. I’m not as fragile as I may appear. I accept my MDS as just another of life’s challenges. Cancer defines a disease not a person. And lastly, no matter what – I’m Still Me”



MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

Clinical Trials in MDS

YouAndMDS.com

Developed by the Myelodysplastic Syndromes Foundation, Inc. and Mechanisms in Medicine Inc.



YouAndAML.com

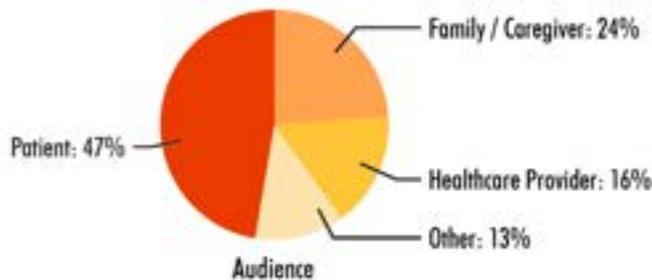
An Animated Patient's Guide to Acute Myeloid Leukemia
Outcomes & Metrics Report • November 2019 - March 2025

Audience Reach and Demographics



USA Unique Visitors

- Patients = 71,270
- Family / Caregivers = 36,393
- Healthcare Providers = 24,262
- Other = 19,713
- TOTAL = 151,638**



Patients Who Reported Commitment to Change



93% will use information learned to better self-manage their AML



94% plan to discuss information learned with their doctor



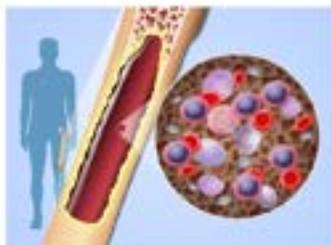
98% plan to discuss AML medication and treatment options with their doctor



84% will take a list of questions about AML to their next doctor's visit



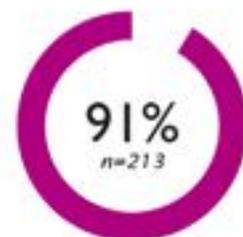
72% plan to reach out to MDS Foundation for support



Patients Who Learned New Information on AML



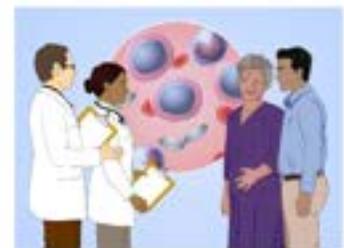
93% learned new general information about AML



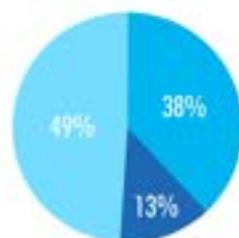
91% learned new diagnosis information about AML



94% learned new treatment option information for AML



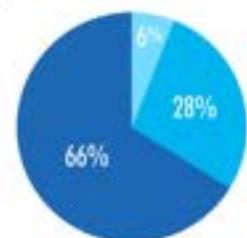
Patient Pre-/Post-Website Knowledge Level



Pre-website
n=211

Response:

- Low
- Medium
- High



Post-website
n=211



YouAndMDS.com

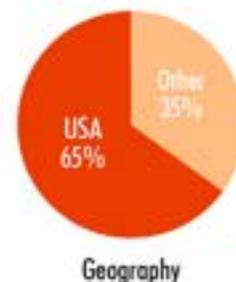
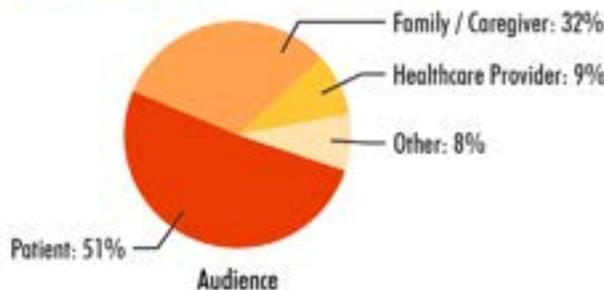
Animated MDS Patient: An Animated Patient's Guide to Myelodysplastic Syndromes
Outcomes & Metrics Report • July 2018 - March 2025

Audience Reach and Demographics



USA Unique Visitors

- Patients = 156,778
- Family / Caregivers = 98,370
- Healthcare Providers = 27,667
- Other = 24,593
- TOTAL = 307,408**



Patients Who Reported Commitment to Change



95% will use information learned to better self-manage their MDS



92% plan to discuss information learned with their doctor



96% plan to discuss MDS treatment options with their doctor



82% will take a list of questions about MDS to their next doctor's visit



68% plan to reach out to MDS Foundation for support



96% plan to discuss how they can take part in healthcare decisions

Patients Who Learned New Information on MDS



95% learned new general information about MDS



87% learned new diagnosis information about MDS

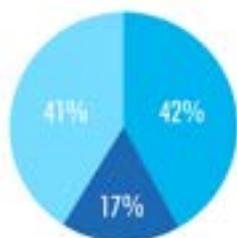


86% learned new treatment option information for MDS



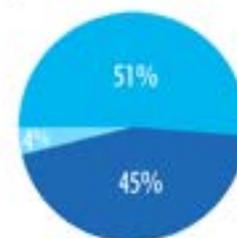
83% learned new blood and marrow transplant information for MDS

Patient Pre-/Post-Website Knowledge Level



Response:

- Low
- Medium
- High





UPCOMING 2025 WEBINARS FOR MDS PATIENTS & CAREGIVERS

MDS is one hard-to-define, hard-to-treat disease.

Participating in an MDS Foundation Webinar is a convenient way to get real information on the latest developments – ideas that could change your outlook as well as your treatment protocol.

- All have a live Q&A session with the expert speakers
- Webinars are recorded and available after the event
- Average length is 1 – 1.5 hours
- MDSF staff moderated
- Topics will be based on the results of the annual MDSF Patient and Caregiver Survey

Caregiver Burnout / Self-Care

April 26, 2025

Disease Related Fatigue

November 22, 2025

Stem Cell Transplants and Cell Therapies for MDS

June 7, 2025



FREE ONLINE WEBINAR

Register today:



MDS-Foundation.org/events/webinars



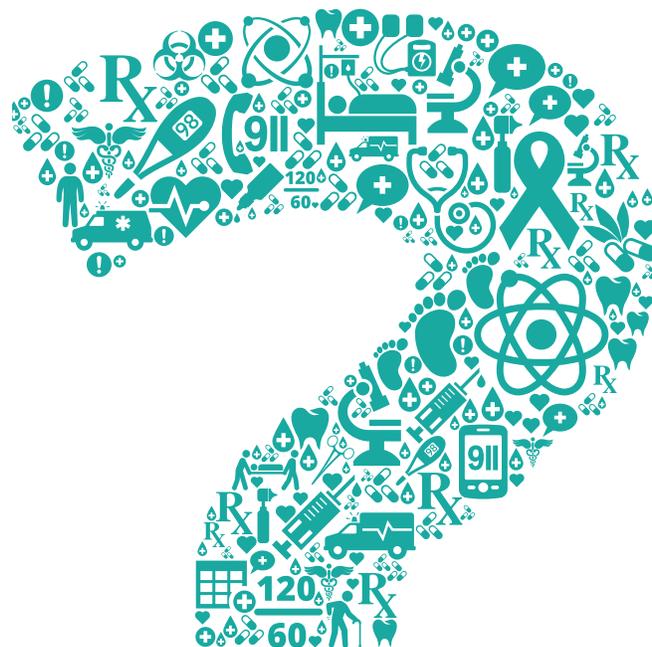
**We are the people
who make hope work.**

Thank you to Taiho Oncology for supporting these important events.



**Questions
about MDS?
Need support
or resources?**

**Contact our
Director of
Patient Care now.**



You are not on your own. The MDS Foundation supports and educates patients, communities and healthcare providers. We help accelerate innovative research in MDS and its related diseases to better diagnose, control and ultimately cure them. We can help you. We are the people who make hope work.

Educate • Communicate • Advocate

**Ashley Moncrief RN, BSN, Director of Patient Care:
1-800-637-0839 ext. 210 • amoncrief@mds-foundation.org**

mds-foundation.org



BE A LIFE-CHANGING FORCE.

MDS is not incurable. It simply hasn't been cured yet.

But with your help, that day is coming. Your donation turns hope into reality. For over 30 years, The Myelodysplastic Syndromes Foundation has been a catalyst for progress: Supporting patients. Expanding education. Accelerating research. Bringing critical awareness of MDS to the world. We depend on your investment to make this progress happen.

To provide the services we do, The MDS Foundation needs your help. We have a goal in 2025 to raise \$1 million in private dollar support from people like you – people who have been touched by MDS either personally or through someone they love.

The dollars raised will support critical research initiatives, provide resources to patients and their families, spread awareness about MDS, and allow us to continue the work we have been doing for over 30 years.

Donate today and be a life-changing force. Give at www.mds-foundation.org/donate

For questions about donations, contact Tanya Rhodes, Director of Development at trhodes@mds-foundation.org or 609-298-1600 x205



**Scan to
Donate**



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.



**REGISTER
HERE**

UPCOMING EVENTS

- **May 10, 2025**
Rotterdam, The Netherlands
- **September 13, 2025**
Little Rock, Arkansas
- **September 27, 2025**
Cleveland Clinic, Cleveland, OH
- **October 18, 2025**
University of Nebraska Medical Center, Omaha, NE
- **November 8, 2025**
Emory University Hospital, Atlanta, GA



ADDITIONAL INFORMATION

- Breakfast and lunch are provided
- Information packet provided at the event
- Parking is complimentary
- Events are held on Saturdays
- Opportunity to meet MDS providers, MDSF staff, and other MDS patients.

REGISTRATION IS REQUIRED

DON'T MISS OUT ON THESE INFORMATIVE, FREE EVENTS.

Thank you to BMS, Servier and Taiho Oncology for sponsoring these events.

WANT TO HAVE A PATIENT FORUM NEAR YOU?

Reach out to Janice Butchko (jbutchko@mds-foundation.org), to advocate for a forum in your community!



THE MDS FOUNDATION MESSAGE BOARD

You are not alone. . . support is only a click away.

THE MDS EXCHANGE IS NOW LIVE!

The MDS Foundation is excited to announce the transition of the MDS Message Board to our new and enhanced platform - MDS Exchange.

MDS Exchange is a safe space to connect with the MDS community, share your story, and find support. This upgrade provides a more user-friendly interface, new features for deeper engagement, and ensures that the MDS community can continue to connect, share, and support each other with even greater ease.

The MDS Exchange offers a range of new features designed to make the platform more intuitive and engaging.

These include:

- **ENHANCED DISCUSSION BOARDS:**
Participate in a variety of discussions, including managing symptoms, treatment options, and more
- **COMMUNITY SUPPORT:**
Connect with others in the MDS community—patients, caregivers, and advocates—and receive encouragement and support
- **ASK QUESTIONS AND GET ANSWERS:**
Post questions and receive insights from like-minded people who understand your journey
- **OUR AMBASSADORS:**
Engage with ambassadors—patients, caregivers, and experts—who foster meaningful conversations and help ensure the patient voice is always central

HOW TO GET STARTED

If you were previously a member of the MDS Message Board, no action is required on your part. Your sign-in details have been securely transferred to the new platform, allowing you to continue engaging with the community without interruption.

For new members, joining is easy. Simply register for an account, and you'll be able to start participating in discussions and accessing valuable resources right away.



Please note: The MDS Foundation does not provide medical treatment or advice. It is not subject to HIPAA and cannot guarantee the privacy of any medical records or health information you disclose to us.

2025 Patient & Caregiver Survey



Your voice matters!

The MDS Foundation would like to understand more about you (the MDS patient and the MDS caregiver), your health, and your educational and support needs. Topics for Foundation initiatives (podcasts, forums, webinars, online content) are selected based on the unmet needs identified in the survey.

THE SURVEY IS NOW LIVE!

All answers are confidential – no patient or caregiver identifiers are included (for example name, date of birth, address).

All answers will be compiled into a summary document to assist in planning and development of programs for support of patients and caregivers living with MDS and may be used in presentations on behalf of the MDS Foundation.



THE MDS FOUNDATION'S
GUIDE TO ASSISTANCE PROGRAMS
IN THE UNITED STATES

PLEASE SCAN TO RECEIVE YOUR GUIDE

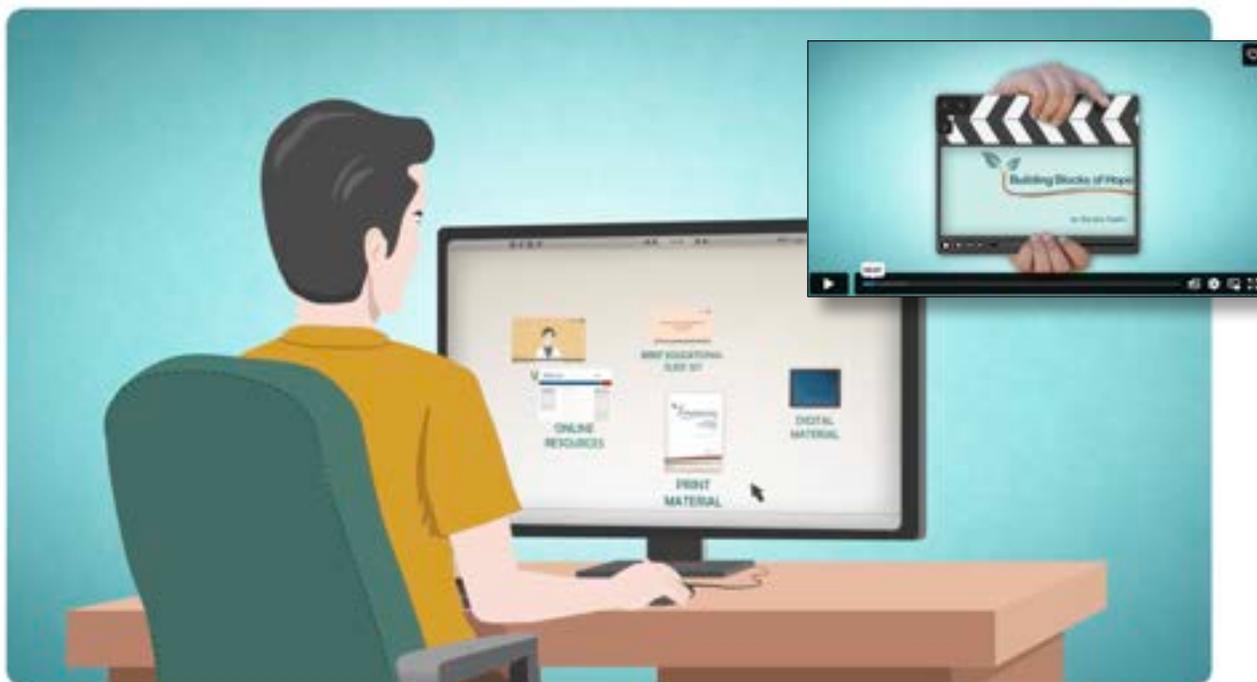
GUIDE TO ASSISTANCE PROGRAMS IN THE UNITED STATES

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.

Building Blocks of Hope (BBoH)

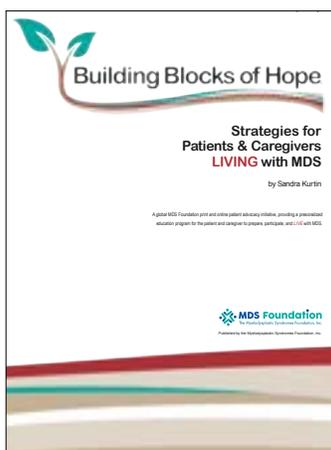
PATIENT RESOURCE

This program is designed to give patients and caregivers the in-depth information that they are looking for and to allow them to take an active part in their MDS journey.



BBoH VIDEO

www.mds-foundation.org/resources/materials/building-blocks-of-hope-bboh



ORDER YOUR COPY TODAY!

www.mds-foundation.org/resources/order-form

Available in MDS, AML and MPN



SHARE TO INSPIRE

Because your story can help inspire another.

If you're being treated with REBLOZYL® (luspatercept-aamt), what you have to say could **make a difference** in another person's life.

Find out how you can **"share to inspire"** and use your experience for the greater good.



Call us toll-free at **1-855-436-5866** or visit **ShareToInspire.com**

Reblozyl®
(luspatercept-aamt)
for injection 25mg • 75mg

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 Bristol Myers Squibb®

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2007-US-2400375 10/24



 SHARE TO INSPIRE



ONE
TWO
THREE
ACCESS!

Helping patients obtain access to
Taiho Oncology medicines

Learn about our hematology product at
TaihoOncology.com/US/

CALL 1-844-TAIHO-4U [1-844-824-4648]
FAX 1-844-287-2559
VISIT TaihoPatientSupport.com

 TAIHO ONCOLOGY
PATIENT SUPPORT
Supporting your treatment journey

 TAIHO ONCOLOGY

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AVAILABLE NOW!

JOE IN AML

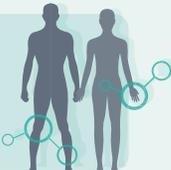
Representing a nucleus, **JOE** collates information and resources together in one place. JOE invites the AML patient community to embark on a Journey Of Empowerment, **allowing them to be their own best advocates.**



Module 1
The essential facts of AML



Module 2
Understanding the impact of AML on your body



Module 3
Understanding your AML diagnosis



Module 4
Managing the signs and symptoms of AML



Module 5
Treatment of AML



Module 6
Patient empowerment



LEARN MORE

www.mds-foundation.org/resources/apps

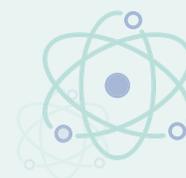


SCAN ME



#amlJOE

AML JOE is brought to you by the MDS Foundation



JOE IN MDS: FRESH LOOK, NEW FEATURES

Since our March 2023 launch, we have taken feedback from patients, caregivers, and healthcare professionals to enhance the learning experience of **JOE in MDS**.

The platform is now available with a **range of new features** designed to educate and empower throughout the MDS journey.



More visuals and diagrams



Updated dashboard



Improved user experience



Content updates



New quiz questions



Resource section



Tailored learning



VISIT TODAY TO EXPLORE THE UPDATES

www.mds-foundation.org/resources/apps/



SCAN ME



#mdsJOE

MDS JOE is brought to you by the MDS Foundation

Memory Wall

“THE ONES WE LOVE NEVER GO AWAY. THEY WALK BESIDE US EVEN ON THIS DAY. UNSEEN, UNHEARD, YET ALWAYS NEAR. STILL LOVED, STILL MISSED, AND VERY DEAR.”

UNKNOWN



Share a memory online



www.mds-foundation.org/community/memory-wall



MDS PATIENT & FAMILY PODCAST 2025

This 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.

New topics coming soon!

MAIN HOST/FACILITATOR:

Nikolaos Papadantonakis MD, MSc, PhD
Associate Professor | Emory University
Department of Hematology and Medical Oncology



ADDITIONAL INFORMATION:

- 4 episodes are planned for 2025
- Guest speakers will be invited to participate.
- Previous seasons are accessible on our website.
- Range from 30 – 45 minutes per episode.

LISTEN ON:



APPLE PODCASTS



SPOTIFY



CASTBOX



RSS FEED



INVEST IN A FUTURE AND MAKE AN IMPACT: YOUR LEGACY WITH THE MDS FOUNDATION

At The MDS Foundation, we believe that lasting change is built over time — and with your help, we can continue to make a difference for MDS patients, their loved ones, and the medical professionals treating this disease. A planned gift is a powerful way to leave a legacy that reflects your values, your passions, and your commitment to the MDS Foundation.

WHAT IS PLANNED GIVING?

Planned giving allows you to make a significant gift to The MDS Foundation during your lifetime or as part of your estate planning. Whether through a bequest in your will, a charitable trust, or other options, your gift will help ensure that the work you care about continues far into the future.

WHY PLANNED GIVING MATTERS

Your planned gift will provide a lasting foundation for The MDS Foundation to carry out its mission, whether it's funding research, advocacy, or providing much needed services to other MDS patients and their loved ones. Your commitment ensures that many will benefit from the work you are helping to build today.

WAYS TO GIVE:

- **Bequests:** Include the MDS Foundation in your will or trust. Your gift can be a specific amount, a percentage of your estate, or the residual of your estate after other bequests.
- **Retirement Accounts & Life Insurance:** Name The MDS Foundation as a beneficiary of your retirement account or life insurance policy.
- **Donor-Advised Funds (DAFs):** Contribute to a DAF and direct grants to The MDS Foundation over time.
- **Gifts of Real Estate or Securities:** Donate property, stocks, or other assets that may provide you with tax benefits while advancing our mission.

Contact Tanya Rhodes, Director of Development, to learn more and to discuss the difference you can make. trhodes@mds-foundation.org or 609-298-1600 x205

**KNOW
AML**

I'm supporting AML World Awareness Day

April 21, 2025



In collaboration with



CANCERCARE

Thank you to our official financial supporters, Kura Oncology, Syndax, and Thermo Fisher Scientific: supporters have no influence on the Know AML content.

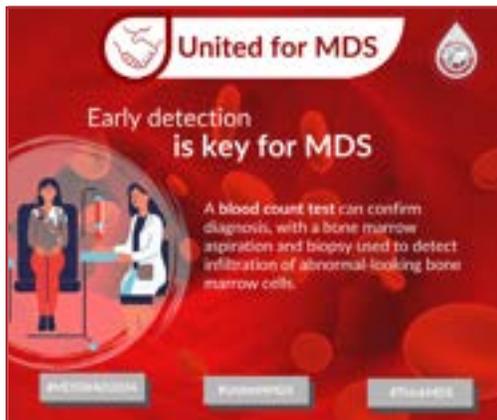
To **LEARN MORE** about AML, visit
<https://www.mds-foundation.org/learn/what-is-aml>
or **SCAN** the QR



MDS Foundation

The Myelodysplastic Syndromes Foundation, Inc.





MDS WORLD AWARENESS DAY IS OCTOBER 25!

DID YOU KNOW? Early detection is key with myelodysplastic syndromes (MDS)! It is often diagnosed through low blood counts, though some patients may show elevated white blood cells or platelets. A blood count test can confirm diagnosis, with a bone marrow aspiration and biopsy used to detect infiltration of abnormal-looking bone marrow cells. Whether it's providing useful information like this or sharing experiences to help patients understand their options, patient organizations play an important role in guiding MDS patients through their diagnosis and treatment.

DISCUSSING MYELODYSPLASTIC SYNDROMES (MDS) WITH A HEALTHCARE PROFESSIONAL IS ESSENTIAL

Open and honest conversations with your care team are key to understanding your condition and making informed treatment decisions.

CONSIDER ASKING THESE QUESTIONS:

- What type of MDS do I have, and how does it differ from other blood cancers?
- Which risk group does my MDS fall into, and how will this affect my prognosis and treatment options?
- Which treatment do you recommend, and why? How will it impact my daily life?
- Are there patient organisations I can contact for more information and support?



No question is too small. A better understanding can help you feel more in control and prepared.

Don't hesitate to ask for further assistance or to contact patient organizations!

Your healthcare team, including doctors, nurses, social workers, and more, is here to support you.

Shared **experiences** have the power to **change the story** for this generation of patients, caregivers and survivors, **and the next.**

Voice them.

CANCER EXPERIENCE REGISTRY SURVEY

We are excited to join forces with Cancer Support Community to share their newly launched MDS Cancer Experience Registry (CER). The Cancer Experience Registry is a free and confidential online survey for anyone who has ever been diagnosed with cancer, and for caregivers of individuals with cancer, to share their cancer experience. The findings gathered from these surveys will illustrate the Cancer Support Community's commitment to putting the voices of patients and caregivers at the center of the conversation about cancer. By taking the survey, you join thousands of others in helping to: influence health care policies, enhance cancer care, and improve support services. Join today and elevate your voice!



Use the QR code to take the survey

www.cancerexperienceregistry.org/join/MDSF



CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER



MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

Consider your next step with anemia caused by MDS

The ELEMENT-MDS Study is now enrolling adults who have low or intermediate risk Myelodysplastic Syndrome (MDS) and are not receiving blood transfusions, and you may be able to take part.

Researchers are evaluating if the investigational study drug may have the potential to help prevent or delay the need for blood transfusions.

Compensation for time and travel may be available.

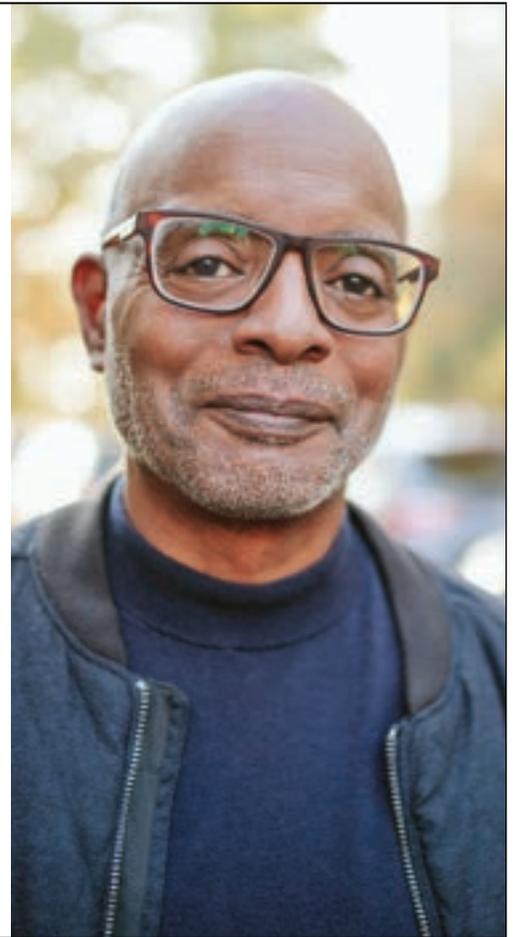


To learn more, scan the QR code or visit BMSClinicalTrials.com/ELEMENTMDS.

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ELEMENT-MDS
First Line NTD 



GLOBAL MDS PATIENT SUPPORT GROUPS

The MDS Foundation is proud to partner with MDS-specific patient support groups globally, offering a crucial space for connection, education, and shared experiences.

We're seeking new support group leaders to help grow our network and provide essential support to MDS patients and caregivers. If you're interested in leading a group in your community, we'd love to hear from you.

We provide both administrative and financial support for those looking to start a group in their area.



SCAN FOR MORE
INFORMATION

Learn more about starting or joining a support group at
www.mds-foundation.org/community/support-groups



WELCOME TO THE PROFESSIONAL SECTION OF THE MDS FOUNDATION NEWSLETTER



PROFESSIONAL MEMBERSHIP



Unlock exclusive benefits, contribute to a global network of professionals, and make a lasting impact in the fight against MDS. Your expertise is a valuable addition to our community. Join now and be a driving force for positive change.

USE THIS QR CODE TO SIGN UP TODAY!

EXCLUSIVE BENEFITS

- Members only access to Young Investigator Grant programs and/or abstract applications
- Free shipping of educational materials
- *Leukemia Research* subscription discount
- Discounts to MDSF professional programs (congresses, symposia)
- Receipt of MDS Foundation printed newsletters
- Expedited listing of MDS/CHIP/CCUS/sAML clinical trials on our clinical trial portal

MEMBERSHIP FEES

- Student membership (new rate) - \$50
- Student membership + *Leukemia Research* subscription - \$190
- Professional membership - \$125
- Professional membership + *Leukemia Research* subscription - \$265



THE MDS PROFESSIONAL REPORT PODCAST

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 give us an easy and popular way to communicate this information in a short time.



USE THIS QR CODE TO LISTEN TODAY!

<https://www.mds-foundation.org/professional/resources/podcast>



MDS Risk Assessment Calculators

The International Working Group for Prognosis in MDS (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).

CLINICAL DATA

*Bone Marrow Blasts
Percentage [0-30%]

*Hemoglobin
g/dL [4-20 g/dL]

*Platelet Count
10⁹/L [0-2000 10⁹/L]

OPTIONAL IPSS-R DATA

Absolute Neutrophil Count
10⁹/L [0-15 10⁹/L]

Age
Years [18-100 years]



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-risk-model.com>

DOWNLOAD IPSS-M CALCULATOR APP

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



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://ipssradvanced.mds-foundation.org>

DOWNLOAD IPSS-R CALCULATOR APP



Scan for
iOS App



Scan for
Android App

YOUNG INVESTIGATOR GRANTS

Congratulations to our 2025 Young Investigator Grant Winners!

MDS Foundation, Inc.'s Young Investigator Grant provides an investigator, that is early in their career, the opportunity to initiate, continue or complete a project that focuses on either basic or clinical management into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis and treatment of the myelodysplastic syndromes.



Sydney Lu, MD, PHD

MDS Foundation Young Investigator Award Winner

FUNDED BY: MDS Foundation, Inc.

GRANT YEAR: 2025–2027

RESEARCH CENTER: The Board of Trustees of the Leland Stanford Junior University, Redwood City, California

RESEARCH TITLE: *Novel mechanisms of oncogenesis for SRSF2 mutations*

SUMMARY: Recurrent oncogenic mutations of SRSF2 are common in MDS and have been scrutinized for alterations of RNA splicing. We have recently identified them to also mediate pervasive alterations to transcript 3' end formation, dysregulating key target genes such as BRD4. We now hypothesize that SRSF2 mutations alter transcript 3' end formation to regulate MDS biology. Our aims are to 1. Identify alterations of splicing and transcript 3' end isoforms in SRSF2 mutant myeloid neoplasms with a focus on primary patient specimens and 2. Investigate the role of altered transcript 3' end formation due to SRSF2 mutations on oncogenesis.



Lin-Pierre Zhao, MD, PHD

MDS Foundation Young Investigator Award Winner

FUNDED BY: MDS Foundation, Inc.

GRANT YEAR: 2025–2027

RESEARCH CENTER: Inserm Délégation Régionale Paris-IDF Centre Nord, Paris, France

RESEARCH TITLE: *Unraveling the Immune Impact of Clonal Hematopoiesis and Myelodysplastic Syndromes Through Their Interaction with Immune-Mediated Inflammatory Disorders*

SUMMARY: The interplay between clonal hematopoiesis (CH), myelodysplastic syndromes (MDS), and immune-mediated inflammatory disorders (IMIDs) remains poorly understood, despite emerging evidence of shared pathogenic mechanisms. This project investigates their interactions through large-scale epidemiologic studies, murine arthritis models, and multiomics analyses to elucidate the impact of CH on immune dysregulation. By identifying CH-driven inflammatory pathways and therapeutic targets, we aim to refine precision medicine approaches and establish CH as a key player in systemic inflammation and disease progression.

WITH SINCERE
THANKS



This publication is provided to you on behalf of the MDS Foundation, with generous support from Taiho Oncology.

MDS Centers of Excellence

Our MDS Centers of Excellence are institutions that meet the highest standards for diagnosis, treatment and patient care. These centers help patients seeking first or second opinions and/or additional treatment options from experts in MDS. We currently have 77 Centers in the United States and 121 Centers in countries around the world.

<https://www.mds-foundation.org/mds-centers-of-excellence>



BENEFITS OF MEMBERSHIP:



- MDSF CoEs form the referral base for the patients who contact the Foundation daily.
- MDSF CoEs are proudly recognized on the Foundation website, within our printed newsletters, and through our various social media platforms.
- MDSF CoEs are offered discounted registration rates at MDS Foundation meetings and a 60% annual subscription discount to *Leukemia Research*.
- MDSF CoEs have full access to MDSF educational resources for distribution to your patients.
- In addition, along with your \$500 CoE renewal payment, your annual MDSF Professional Membership dues are waived.
- 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:

- Available cytogenetics and/or molecular genetics
- Ongoing research, including Institutional Review Board-approved clinical trials
- Recognized morphologic expertise in MDS
- Documentation of peer-reviewed publications in the field
- Affiliation with an academic institution: If not affiliated, other justifying evidence may be submitted as criteria has changed.

For more information or to apply, please contact Ashley Moncrief, Director of Patient Care, at amoncrief@mds-foundation.org.
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

ARKANSAS

**University of Arkansas
for Medical Sciences**

Little Rock, Arkansas
Muthu Veera Kumaran, MD
Ankur Varma, MD

ARIZONA

Mayo Clinic Hospital

Phoenix, Arizona
Cecilia Arana Yi, MD/James Slack, MD

The University of Arizona Cancer Center

Tucson, Arizona

CALIFORNIA

**Cedars-Sinai Medical Center
UCLA School of Medicine**

Los Angeles, California
H. Phillip Koeffler, MD

City of Hope National Medical Center

Duarte, California
Stephen J. Forman, MD

Moore's 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
Advent Health Cancer Institute**

Orlando, Florida

Mayo Clinic

Jacksonville, Florida
James M. Foran, MD

Moffitt Cancer Center

Tampa, Florida
Rami Komrokji, MD
Alison R. Walker, MD

MDS FOUNDATION CENTERS OF EXCELLENCE

**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
Gerik Sutamtewagul, MD

KANSAS**The University of Kansas Cancer Center**

Westwood, Kansas
Jesus Gonzalez Lugo

MARYLAND**Johns Hopkins University
School of Medicine**

Baltimore, Maryland
Amy Elizabeth DeZern, MD

**University of Maryland
Greenebaum Cancer Center**

Baltimore, Maryland
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MASSACHUSETTS**Dana-Farber/Boston Children's Cancer
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Dana-Farber Cancer Institute

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Benjamin Ebert, MD, PhD

**Massachusetts General Hospital
Cancer Center**

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Timothy Graubert, MD

Tufts Medical Center

Boston, Massachusetts
Andreas Klein, MD

MICHIGAN**Barbara Ann Karmanos Cancer Institute
Wayne State University**

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Jay Yang, MD

**William Beaumont Hospital Cancer
Center (now Corewell Health)**

Royal Oak, Michigan
Ishmael Jaiyesimi, DO

MINNESOTA**Mayo Clinic**

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Mrinal S. Patnaik, MBBS

**University of Minnesota
Medical Center, Fairview University
of Minnesota Medical School**

Minneapolis, Minnesota
Mark B. Juckett, MD/Jeremy Allred, MD

MISSOURI**Washington University School of Medicine
Siteman Cancer Center**

St. Louis, Missouri
John F. DiPersio/Meagan Jacoby, MD
Matt Walter, MD

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**

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**Rutgers Cancer Institute of New Jersey
Rutgers University Hematologic
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NEW MEXICO**University of New Mexico
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**Laura & Isaac Perlmutter Cancer Center
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**Wake Forest University
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**Union Hospital,
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Yu Wu, MD

**Xiangya Hospital
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Ling Nie, MD

**Zhongda Hospital,
Southeast University**

Zhongda, China
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Claus Marcher, MD

Rigshospitalet National University Hospital
Copenhagen, Denmark
Kirsten Grønbaek, MD
Lars Kjeldsen, MD, PhD

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Rouen University School of Medicine**
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Angers, France
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Jean-Yves Cahn, MD

Centre Hospitalier Universitaire (CHU) de Limoges Hôpital Dupuytren
Limoges, France
Pascal Turlure, MD

Centre Hospitalier Universitaire (CHU) de Nancy
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Tours, France
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Paris, France
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Hôpital Saint Louis/University Paris VII
Paris, France
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Christine Chomienne, MD, PhD

Hôpital Saint-Vincent de Paul (Lille)
Lille, France
Pascal Laurent, MD

Institut Paoli-Calmettes
Marseille, France
Norbert Vey, MD

Service des Maladies du Sang Hôpital Claude Huriez
Lille, France
Bruno Quesnel, MD

GERMANY

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Göttingen, Germany
Detlef Haase, MD, PhD

**Hannover Medical School
Medizinische Hochschule Hannover**
Hannover, Germany
Matthias Eder, MD, PhD

Heinrich-Heine Universität Düsseldorf University Hospital
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Ulrich Germing, MD

Johannes Gutenberg University Medical Center Mainz
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Markus Radsak, MD, PhD

Johann Wolfgang Goethe Universität III
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**Klinikum Rechts der Isar
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Heinrich-Heine Universität**
Duisburg, Germany
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Albert-Ludwigs-Universität Freiburg
Freiburg, Germany
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UPDATES FROM MDS CENTERS OF EXCELLENCE

The Ohio State University Comprehensive Cancer Center

ON BEHALF OF DR. UMA BORATE: The Ohio State University Comprehensive Cancer Center would like to announce their new publication in *Blood* on March 27, 2025. The entry, titled "Reducing Clinical Trial Eligibility Barriers for Patients with MDS: an icMDS Position Statement", covers MDS clinical trials and eligibility criteria. The full article can be found at the link below.

ashpublications.org/blood/article/145/13/1369/534836/Reducing-clinical-trial-eligibility-barriers-for

Vanderbilt University Medical Center

ON BEHALF OF DR. SOMEDEB BALL: Vanderbilt-Ingram Cancer Center recently opened a NIH funded IST - Eltanexor and Venetoclax in Relapsed or Refractory Myelodysplastic Syndrome and Acute Myeloid Leukemia. They are actively looking for patients. For more information, visit:

clinicaltrials.gov/study/NCT06399640

Sylvester Comprehensive Cancer Center

The 4th Biennial Miami Leukemia Symposium is being held on April 25, 2025 – April 27, 2025 at the Ritz Carlton in Coconut Grove.

The retreat will feature in-depth and engaging discussions on current management practices, recent clinical and translational breakthroughs, and innovative treatment strategies for Acute Myeloid Leukemia, Acute Lymphoblastic Leukemia, and Myelodysplastic Syndromes. Link to register:

web.cvent.com/event/83501e60-fa22-4726-a228-9523b227b416/summary

University Hospital Freiburg – Germany

ON BEHALF OF DR. CHARLOTTE NIEMEYER: The European Working Group of Myelodysplastic Syndrome Childhood (EWOG-MDS) and Severe Aplastic Anemia (EWOG-SAA) will host the 11th International Symposium EWOG-MDS and SAA in Childhood "On the verge to malignancy: Cytopenia and beyond" in Berlin, Germany, September 18–20, 2025.

The symposium is hybrid since not all interested colleagues can participate in person. We will be delighted to meet them online. The early bird rates until May 15, 2025. Registration form can be found on the website of the Symposium at:

ewogberlin2025.org/y

MDS FOUNDATION CENTERS OF EXCELLENCE



Welcome to our new MDS Centers of Excellence!

The MDS Foundation welcomed **18 new Centers of Excellence** during quarter 4 of 2024 and quarter 1 of 2025.

Being a Center of Excellence (CoE) is more than a designation, it is an invitation to a community of patient-focused, research-driven professionals. We are excited about these new partnerships and look forward to future collaborations.

CHINA

Tongji Hospital, *Prof. Jia Wei, MD, PhD*

Tianjin Medical University General Hospital, *Rong Fu, BM, MM, PhD*

The First Affiliated Hospital of Guangxi Medical University, *Liu Zhenfang, PhD, MD*

The First Affiliated Hospital of Wenzhou Medical University, *Sheng Luo, Associate Chief Physician*

Department of Hematology, Union Hospital, Tongji Medical College, *Mei Hong, Professor*

Qilu Hospital of Shandong University, *Shuqian Xu, PhD, Deputy Director of the Red Cell Disease Department*

Jiangsu Province Hospital, also known as the First Affiliated Hospital with Nanjing Medical University
Shen Wenyi, MD, Chief Physician

Fujian Medical University Union Hospital, *Yan Juan Lin, MD, PhD, Chief Physician*

The First Affiliated Hospital of the USTC, as the provincial medical center of Anhui
Zhu Xiaoyu, MD, PhD, Attending Physician/PI for Referrals: Na Zhao

Guangzhou First People's Hospital, *Wang Shunqing, MD*

The Second Hospital of Hebei Medical University, *Wang Ying, Professor*

Zhongda Hospital, Southeast University, *Zheng Ge, MD, PhD, Director/Chair of Department of Hematology*

The Department of Hematology, Ruijin Hospital, Shanghai Jiao Tong University School of Medicine
Sujiang Zhang, Chief Physician

Xiangya Hospital of Central South University, *Ling Nie, MD*

Peking Union Medical College Hospital, *Bing Han, Professor*

The First Affiliated Hospital of Xinjiang Medical University, *Dr. Jianping Hao*

West China Hospital of Sichuan University, *Yu Wu, MD*

AUSTRALIA

Calvary Mater Newcastle Australia, *Anoop K Enjeti, MBBS, MD, FRCP, FRCPA, PhD*

If your institution is interested in becoming an MDS Center of Excellence, reach out to the Foundation's Director of Patient Care Ashley Moncrief for additional information via email at amoncrief@mds-foundation.org.



MDS Foundation Centers of Excellence

SPOTLIGHT ON UNIVERSITY OF KANSAS CANCER CENTER

GET TO KNOW THE STAFF AT UNIVERSITY OF KANSAS CANCER CENTER



JESÚS GONZÁLEZ LUGO, M.D.

*Division of Hematologic Malignancies and Cellular Therapeutics
University of Kansas Cancer Center*

BACKGROUND

I completed my internal medicine residency at the Albert Einstein College of Medicine. Afterward, I pursued a Hematology and Oncology Fellowship at the Montefiore Medical Center, Albert Einstein College of Medicine, where I served as chief fellow. I specialize in Myelodysplastic Syndromes and Acute Leukemias. Additionally, I am an active clinical researcher with phase 1 and phase 2/3 clinical trials for MDS and AML. I currently hold the position of Assistant Professor of Medicine at the University of Kansas Medical Center.

HOW HAVE YOU BEEN INVOLVED WITH THE MDS FOUNDATION?

I have been involved with the MDS Foundation since my training as a hematology-oncology fellow. I held a weekly MDS clinic, trained at a center of excellence, received numerous patient referrals, and provided educational brochures to patients. Now that I practice medicine, I serve as the primary contact for the MDS Foundation at our center; we ensure that we deliver the best care through the foundation and offer our expert opinions. I have attended international MDS Foundation Congresses, and we are planning to host a patient and caregiver forum soon in Kansas City.

WHAT INSPIRED YOU TO GO INTO THE FIELD OF HEMATOLOGY?

My own experience with leukemia and undergoing chemotherapy inspired me to go into hematology. I decided to dedicate my life to caring for patients with hematological malignancies.

DO YOU HAVE ANY ADVICE FOR OUR READERS?

I have a few pieces of advice for patients. The first is to try not to think about your illness all the time. Instead, aim to live as normally as possible, enjoy your family and friends, and avoid letting the illness consume you and dictate your life. The second point is that if you feel something isn't right, if something is being dismissed, or if you sense that something is off or not working, look for a second opinion.

PROFESSIONAL MEETING ANNOUNCEMENTS



Dear Colleague and Friends,

Berlin meets EWOG – EWOG meets the world! The European Working Group of Myelodysplastic Syndrome Childhood (EWOG-MDS) and Severe Aplastic Anemia (EWOG-SAA) will host the **11th International Symposium EWOG-MDS and SAA in Childhood “On the verge to malignancy: Cytopenia and beyond”** in Berlin, Germany, September 18–20, 2025.

EWOG-MDS/SAA is a consortium of National Working Groups of clinicians and researchers of 20 European Countries dedicated to diagnose and treat young individuals with acquired and inherited bone marrow failure, predisposition syndromes, MDS and rare MPD in young people. The group organizes an International Symposium biannually to bring together renowned experts in the fields.

In 2025, we will host the EWOG Symposium in Berlin, Germany.

The symposium is hybrid since not all interested colleagues can participate in person. We will be delighted to meet them online. Registration form can be found on the website of the Symposium at: <https://www.ewogberlin2025.org/>

The early bird rates are until May 15, 2025.

Participants from low and mid come countries can ask for virtual participation free of charge.

We are looking forward a very productive and interesting meeting. See you all in Berlin soon!

Sincerely yours,

Charlotte Niemeyer, MD

Chair of the Local Organizing Committee



4th BIENNIAL MIAMI LEUKEMIA SYMPOSIUM

APRIL 25-27, 2025

THE RITZ-CARLTON COCONUT GROVE IN MIAMI, FL

Join Sylvester Comprehensive Cancer Center for an insightful discussion by world-renowned scientists, as they explore the latest advancements in managing acute myeloid leukemia, myeloproliferative neoplasms and myelodysplastic syndromes.

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4th BIENNIAL MIAMI LEUKEMIA SYMPOSIUM

PLENARY SPEAKER

Wendy Stock, M.D., The University of Chicago

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The Ohio State University

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Sunnybrook Health Sciences Centre

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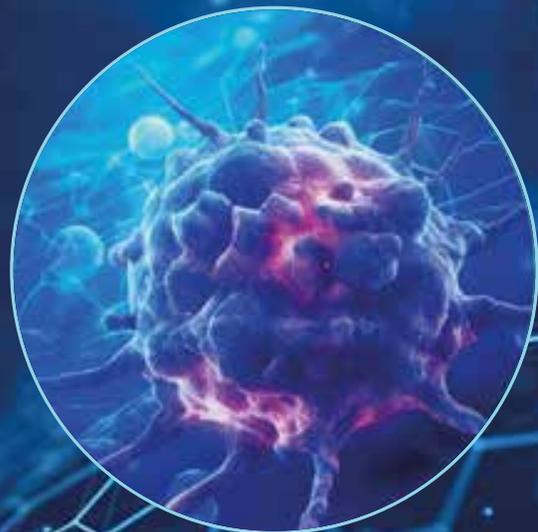


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SPECIAL UPDATES

Latest news regarding projects of the International Working Group for Prognosis in MDS (IWG-PM) coordinated by Peter Greenberg

Several recent publications by members of the IWG-PM led by Elsa Bernard, within the laboratory of Elli Papaemmanuil at Memorial Sloan-Kettering Cancer Center, under the aegis of the MDS Foundation, have provided major new approaches for the prognostication and molecular classification of MDS patients. A recent initial paper produced the clinical-molecular MDS prognostic risk model (IPSS Molecular or IPSS-M).¹ In this study 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 multi-hit 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 and an app were 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. The app is available to supplement the weblink now in general use for calculating the IPSS-M.

Because of the clinical and morphologic heterogeneity of MDS patients, a molecular taxonomic classification of MDS was developed by Bernard and IWG-PM colleagues.² Genomic profiling was performed on 3,233 patients with MDS or related disorders to delineate molecular subtypes and define their clinical implications. Gene mutations, copy-number alterations (CNAs), and copy-neutral loss of heterozygosity (cnLOH) were derived from targeted sequencing of a 152-gene panel, with abnormalities identified in 91, 43, and 11% of patients, respectively. Sixteen molecular groups were defined, encompassing 86% of patients, using information from 21 genes, 6 cytogenetic events, and LOH at the TP53 and TET2 loci. Two residual groups defined by negative findings (molecularly not-otherwise specified, absence of recurrent drivers) comprised 14% of the patients. The groups varied in size from 0.5% to 14% of patients and were associated with distinct clinical phenotypes and outcomes. The median bone marrow blast percentage ranged from 1.5 to 10%, and the median overall survival from 0.9 to 8.2 years. Five well characterized entities were validated, further evidence added support to 3 previously reported subsets, and 8 novel groups were described. The prognostic influence of bone marrow blasts depended on the genetic subtypes. Within genetic subgroups, therapy-related MDS and myelodysplastic/myeloproliferative

neoplasms (MDS/MPN) had comparable clinical and outcome profiles to primary MDS. Thus, genetically-derived subgroups of MDS were shown to be clinically relevant and which should better inform future classification schemas.

Mutations in the UBA1 gene, which are disease-defining for VEXAS (vacuoles, E1 enzyme, X-linked, autoinflammatory, somatic) syndrome, have been reported in patients with MDS. Led by Dr Maria Sirenko, with the IWG-PM, the prevalence and clinical associations of UBA1 mutations in a representative cohort of patients with MDS were defined.³ In a selected cohort of 375 male patients lacking MDS disease-defining mutations or established World Health Organization (WHO) disease classification, 28 patients (7%) were identified with UBA1 p.M41T/V/L mutations. Using targeted sequencing of UBA1 in a representative MDS cohort (n = 2027), an additional 27 variants in 26 patients (1%) were identified. Among the patients with likely/pathogenic variants (2%), all were male and 63% were classified by WHO 2016 criteria as MDS with multilineage dysplasia or MDS with single-lineage dysplasia. Retrospective clinical review showed that 82% UBA1-mutant cases had VEXAS syndrome-associated diagnoses or inflammatory clinical presentation. The prevalence of UBA1 mutations in patients with MDS argues for the need for systematic screening for UBA1 in the management of MDS.

To analyze clinical outcomes of treatment-related MDS (t-MDS), Andrea Kuendgen, Meritxell Nomdedue and IWG-PM colleagues analyzed 1590 such patients compared to 4738 patients with primary MDS (p-MDS).⁴ Cytogenetic profiles were the most distinctive risk factor between t- vs. p-MDS independent of treatment. Normal karyotype, del(5q), +8, del(12p), -13/del(13q), i(17q), -Y, and marker chromosomes were at least twice as frequent in p-MDS, while der(1;7), abnormalities 3q, -7, del(7q), t(11q23), double abnormalities including chromosome 7, and complex abnormalities were more frequent in t-MDS. Not only karyotype risk categories, but also single aberrations were substantially different between t- and p-MDS, with a predominance of lower-risk abnormalities in p-MDS and higher-risk abnormalities in t-MDS. These data aid clinical characterization of these distinctive MDS subtypes.

PUBLICATIONS:

1. Bernard E, Tuechler H, Greenberg PL, Hasserjian RP, ..., Ebert BL, Bejar R, Malcovati L, Cazzola M, Ogawa S, Hellström-Lindberg E, Papaemmanuil E. The Molecular International Prognosis Scoring System (IPSS-M) for risk stratification in MDS. *New Eng J Med Evidence* 2022, 1:Evidoa2200008.
2. Bernard E, Hasserjian RP, Greenberg PL, Arango Ossa JE, Creignou M, ...Papaemmanuil E. Molecular Taxonomy of Myelodysplastic Syndromes and its Clinical Implications. *Blood* 144:1617–1632, 2024.
3. Sirenko M, Bernard E, Creignou M, ..., Papaemmanuil E. Molecular and Clinical presentation of UBA1 mutated MDS. *Blood* 144: 1221–1228, 2024.
4. Kuendgen A, Nomdedue M, Tuechler H, ..., Haase D. A comparison of prognostic variables and cytogenetic aberrations in 1590 patients with therapy-related and 4738 with primary MDS including the influence of treatment in MDS-phase. *Proc International MDS Symposium, Rotterdam, May 2025, #350*

SPECIAL UPDATES

The MDS/MPN international Working Group (MDS/MPN IWG)

The MDS/MPN International Working Group (MDS/MPN IWG) was developed in 2012, and work quickly began to develop specialized disease response criteria for MDS/MPN (Savona et al, 2015), to better understand the biology of CMML, and to begin clinical trials specifically for MDS/MPN patients. Since the publication of the Proposed MDS/MPN Response Criteria in 2015,¹ the clinical trial opportunities for patients with MDS/MPN have dramatically increased. This led to development of MDS/MPN-specific trials led by MDS/MPN IWG members, specifically, the first MDS/MPN IWG international study, ABNLMARRO, an international basket study designed to allow new compounds and combinations of therapy to be introduced easily among MDS/MPN IWG clinical sites which have expertise managing MDS/MPN patients, study the biology and pathophysiology of the diseases, and have multilateral expertise in this area. ABNLMARRO-001 is the first ABNLMARRO IWG study which randomly allocates arms of novel

therapies together with the DNA methyltransferase, ASTX727 (Dec-cedazuridine).² The first arm is completed (novel agent, itacitinib), and a second arm is opening in Q2 2025. In addition, ABNLMARRO 002 is due to start as early as Q3 2025 testing a novel agent in a randomized study of patients with CMML. The MDS/MPN IWG will meet at the outset of the MDS Foundation's 18th International Congress on MDS to discuss the next set of ABNLMARRO studies and other new development in MDS/MPN.

REFERENCES

1. Savona M. R. et al. An international consortium proposal of uniform response criteria for myelodysplastic/myeloproliferative neoplasms (MDS/MPN) in adults. *Blood* 125, 1857–1865, doi:10.1182/blood-2014-10-607341 (2015).
2. Moyo TM. et al. The ABNL-MARRO 001 study: a phase 1-2 study of randomly allocated active myeloid target compound combinations in MDS/MPN overlap syndromes. *BMC Cancer*. 2022(1013):1–15



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SPECIAL UPDATES

MDSF Abstracts for 2025

50TH ANNUAL ONCOLOGY NURSING SOCIETY CONGRESS

Abstract title: Making Metrics Matter – Measuring the Impact of Patient Advocacy

Author: Ashley Moncrief RN, BSN

MDS Foundation

Session date/time: Friday, April 11, 2025, 5:30 PM-7:00 PM

Location: Colorado Convention Center

The abstract will also be published in an online issue of the Oncology Nursing Forum.

18TH INTERNATIONAL CONGRESS ON MYELODYSPLASTIC SYNDROMES (MDS 2025)

Abstract Number: 323

Abstract Title: MDS Patients and Caregivers Lack Knowledge, Require Support, the Disease is Diagnosed Late and is Associated With A Significant Burden

Authors: Ashley Moncrief¹, Lea Harrison¹, Moshe Mittelman²

¹MDS Foundation, ²Tel-Aviv Sourasky Medical Center, Tel-Aviv University, Israel

Location: De Doelen ICC Rotterdam, Netherlands

All abstracts of registered MDS 2025 presenters will be published in the Leukemia Research Journal.

18TH INTERNATIONAL CONGRESS ON MYELODYSPLASTIC SYNDROMES (MDS 2025)

Abstract Number: 363

Abstract Title: Animated Patient's Guide to Myelodysplastic Syndromes – Assessing Patient Understanding, Shared Decision-Making, and Health Outcomes

Authors: Amy DeZern¹, Stephen Nimer², David Sallman³, Rafael Bejar⁴, Casey O'Connell⁵, Valeria Santini⁶, Dale Schaar⁷, Janice Butchko⁸, Ashley Moncrief⁸, David Searle⁹

¹Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University School of Medicine, Baltimore, MD, United States of America, ²Sylvester Comprehensive Cancer Center at the University of Miami Miller School of Medicine, Miami, FL, United States of America, ³Moffitt Cancer Center, Malignant Hematology, Tampa, AL, United States of America, ⁴UC San Diego Health, Medicine, La Jolla, AL, United States of America, ⁵Keck School of Medicine, University of Southern California, Division of Hematology, Los Angeles, CA, United States of America, ⁶AOU Careggi - Department of Experimental and Clinical Medicine University of Florence, MDS Unit, Florence, Italy, ⁷Rutgers Robert Wood Johnson Medical School, New Brunswick, NJ, United States of America, ⁸MDS Foundation, Yardville, NJ, United States of America, ⁹Mechanisms in Medicine, Thornhill, Canada

Location: De Doelen ICC Rotterdam, Netherlands

All abstracts of registered MDS 2025 presenters will be published in the Leukemia Research Journal.

TANDEM MEETINGS OF ASTCT AND CIBMTR

Abstract Title: Understanding the Patient Experience and Potential Barriers to Enrollment and Participation in Cell and Gene Therapy (CGT) Trials in Acute Myeloid Leukemia (AML)

AiThi Sprinkle¹, Angela Chan², Violeta Uy³, Allison Rodriguez⁴, Alyssa Michelle Kanegai⁵, Ashley Moncrief⁶, Brenna O'Brien⁷, Christa Kerkorian⁸, Eyal Attar¹, Darren Johnson¹

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Session date: February 13, 2025

Location: Honolulu, HI

MDSF Quarterly Interaction Metrics

In an effort to mathematically quantify our outreach efforts, the MDSF will now be distributing quarterly interaction metrics.

The staff at the MDS Foundation works hard to support patients and their caregivers. We work to find answers, supply educational resources, provide emotional support, and connect patients with our MDS Centers of Excellence.

The data provided has been pulled from phone inquiries, email communications, and message board posts. Patients, family & friends, and members of the community find us primarily through internet searches. The other two more commonly seen referral sources are our Centers of Excellence partners and word-of-mouth of others who have called in previously.

Although the MDSF serves as an advocate for all who reach out, we know there are still people we are missing. In our *Building Blocks of Hope* publication, we encourage patients to become a partner in their care. In order to do this, patients need to be fully informed on their disease and medical advances over time. As the Director of Patient Care, the highlight of my day is speaking with those impacted by MDS and helping them to decipher the available information. Please refer anyone you feel may benefit from our services to the MDSF. Contact information is listed below. Next quarterly metrics will be reviewed ~April 18, 2025.

Q4:2024

Centers of Excellence Referrals

Boston Children’s Hospital (1); City of Hope (1); Emory (1); Levine Cancer Institute (2); Massachusetts General (1); Memorial Sloan-Kettering (1); MD Anderson (1); Moffitt (2); Ohio State (1); Rutgers (psychology referral) (1); Sylvester Comprehensive Cancer Center (1); Stanford (2); Tata Medical Centre (1); Tel-Aviv Sourasky Medical Center (1); University of Chicago (1); University of Minnesota (1); University of Southern California (1); Weill Medical College of Cornell University (1)

Total Referrals: 22 (18.64% of those who reached out to the MDSF)

Snapshot of Inquiries

Question Type	No. and % of Inquiries from Those who Reached Out
Generalized MDS questions	30 (22.1%)
Looking for educational resources	17 (12.5%)
Discussed clinical trials & SparkCures	13 (9.6%)
Needing financial resources	9 (6.6%)
Questions requiring provider input	5 (3.7%)
Seeking emotional support	36 (26.5%)
Fundraising/donations/volunteers	5 (3.7%)
Seeking information on webinars/forums/events	6 (4.4%)

Q3:2024

Centers of Excellence Referrals

Emory (2); Fox Chase-Temple University (1) Huntsman (1); Mayo – Arizona (1); Memorial Sloan-Kettering (1); Moffitt (2); Novant Health Cancer Institute (1); Ohio State (1); Washington University School of Medicine (1)

Total Referrals: 11 (15.94% of those who reached out to the MDSF)

Snapshot of Inquiries

Question Type	No. and % of Inquiries from Those who Reached Out
Generalized MDS questions	28 (40.58%)
Looking for educational resources	13 (18.84%)
Discussed clinical trials & SparkCures	6 (8.70%)
Needing financial resources	6 (8.70%)
Questions requiring provider input	5 (7.25%)
Seeking emotional support	7 (10.14%)
Fundraising/donations/volunteers	8 (11.59%)
Seeking information on webinars/forums/events	4 (5.80%)

Ashley Moncrief, RN, BSN, Director of Patient Care
1-800-637-0839 ext 210, amoncrief@mds-foundation.org

METRICS

13-WEEK SUMMARY

10/19/2024 – 01/17/2024

No. of unique patients/caregivers who called in:

37

No. of unique patients/caregivers who emailed:

73

Message boards answered: **8**

AS OF 01/17/25:

Assisted **118** different patients/caregivers/friends in 13 weeks (~9.1 patients per week)

13-WEEK SUMMARY

07/20/2024 – 10/18/2024

No. of unique patients/caregivers who called in:

37

No. of unique patients/caregivers who emailed:

22

Message boards answered: **10**

AS OF 10/18/24:

Assisted **69** different patients/caregivers/friends in 13 weeks (~5.3 patients per week)

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