

NEWSLETTER

The Myelodysplastic Syndromes Foundation, Inc.

MAKING HOPE WORK FOR 30 YEARS

Founded 30 years ago
as the first nonprofit 100%
dedicated to MDS.



Moving MDS awareness forward
one step at a time with



Community Walks to Drive Awareness
& Accelerate Research



Check out our highlights for 2024 on page 3

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Tracey Iraca
The MDS Foundation



Dear Friends,

When I contemplate all that the Myelodysplastic Syndromes Foundation (MDSF) has accomplished over the last 30 years, I am truly humbled. What started with a group of dedicated physicians who recognized a need to advocate for, support and educate all Myelodysplastic Syndromes (MDS) patients, caregivers and stakeholders, has grown to include developing patient tools and resources, support groups, forums, community events, referrals to clinical trials, and cutting-edge research, grants for young investigators, an assembly of devoted MDS Centers of Excellence, and a professional membership from across the globe. Although a cure for MDS, beyond transplant, has not yet been found, our devoted MDSF team has supported expert physicians, researchers and industry partners as they approach new treatment options that have greatly improved outcomes and quality of life for our patients and their families.

The landscape of MDS research has drastically shifted and improved over these 30 years.

There are 10x's the number of pharmaceutical companies invested in MDS research, as healthcare professionals and researchers continue to dig into causes, precursors, and how to best slow the progression of MDS. The MDS Foundation is honored to continue to be a beacon of hope to MDS patients and families, and a valuable source of education for patients, caregivers and healthcare providers.

After 20 years working with the MDS community and 7 years as the Executive Director of The MDS Foundation, I could not be prouder of our Foundation as we celebrate our 30th Anniversary! In this bittersweet moment, I would like to share with you that I will be retiring at the end of this year. There are not enough words to express what The MDSF and our community has brought to my life over these 20 years, but I'll try: I've been so fortunate to work with a team of smart, caring and dedicated people who understand the importance of putting the patient first. I've learned more than I thought possible from the passionate healthcare professionals I've worked with who use a community approach to learn and better treat their patients. I've seen the industry partnerships grow from simple transactional support to true partnerships that include the patient voice very early in the research process. Overall, I've seen amazing progress in the field of MDS, and I've built great friendships along the way, which has made each and every day of the last 20 years so valuable.

I'm incredibly optimistic for the future of MDS research and treatment, and I look forward to watching the Foundation continue to grow and strengthen their role in the MDS community.

With the goal of finding a cure within our reach, I know the Foundation will tirelessly dedicate their time and resources to changing the outlook for those affected by MDS in the next 30 years.

All my best,

Tracey Iraca
Executive Director
MDS Foundation

To learn more, visit our website at <https://www.mds-foundation.org>



Community Walks to Drive Awareness & Accelerate Research



The Move for MDS took big steps in 2024, walking through Tampa, Nashville, Chicago, New York and Boston, and raising a cumulative total stretching over \$360,000! THANK YOU to the countless individuals and generous sponsors who played a role in helping us achieve such a tremendous feat for The MDS Foundation and MDS community.

Each and every step we take with Move for MDS is a step in the right direction for those battling MDS and those fighting for a cure. We walk to raise awareness, we walk to support patients and caregivers, we walk to honor those lost, we walk to raise funds for research, to spark hope, and ultimately, to find a cure for every individual affected by MDS.

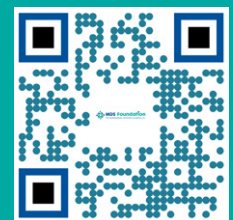
At The MDS Foundation, we're the people who make hope work, and when you join the Move for MDS, you take the first step in joining a team dedicated to leaving an imprint on MDS and every single person it touches.



Consider joining the movement and MOVE with us in 2025!

2025 Dates and Locations COMING SOON!
Visit our Move for MDS page in the coming weeks for 2025 walk schedule

Visit our page



MoveForMDS.org



WE ARE THE MYELODYSPLASTIC SYNDROMES FOUNDATION. WE ARE THE PEOPLE WHO MAKE HOPE WORK.

How exactly do we do that?

WHO IS THE MDS FOUNDATION (MDSF)?

- The first non-profit 100% dedicated to Myelodysplastic Syndromes (MDS), a rare blood cancer.
- A pillar of outreach and support to MDS patients, caregivers and families for 30 years.
- A catalyst helping professional, research and pharmaceutical communities find better treatments and cures.
- Our seminars and symposia provide crucial ongoing medical education for healthcare professionals.



MDSF DELIVERS PATIENT SUPPORT:

- Individual and group support, live forums and webinars for patients, their families and caregivers. All free of charge.
- An MDS expert nurse to answer patient questions and get priority referrals to Centers of Excellence.
- Multiple educational platforms to assist MDS patients and caregivers through their journey.
- Educational materials that reach patients in 20 languages around the world. We are the voice that communicates about MDS and new medical advances.

MDSF CREATES CENTERS OF EXCELLENCE:

- MDSF Centers of Excellence (COEs) are recognized MDS treatment facilities. Each has extensive experience with MDS patients. There are 76 COEs in the U.S. and 118 International COEs.
- COE doctors are MDS experts who set the protocol that other doctors follow. They speak regularly in MDSF webinars, podcasts and patient forums.
- MDSF created the COE program. It provides direct referrals to the closest MDS-specific treatment center and encourages partnership between the COE and local treating physicians.

MDSF DRIVES DIAGNOSIS AND TREATMENT:

- MDSF has strongly impacted the diagnosis of MDS around the world, and built awareness of MDS as not just a blood disorder but as a form of cancer.
- MDSF manages the physician working group that developed the IPSS classification system. This valuable tool helps physicians assess the risk and potential treatments of each MDS case.
- MDSF's clinical trial matching tool helps patients connect with MDS trials.

MDSF ACCELERATES RESEARCH AND CURES:

- MDSF funds research opportunities that allow researchers to initiate, continue or complete projects focusing on MDS through our Young Investigator Grants program.
- Thirty years ago only three pharma companies were pursuing cures and treatments. Thanks to the work of MDSF, today there are over 30 companies worldwide.



MDSF PROVIDES PROFESSIONAL EDUCATION AND PATIENT ADVOCACY:

- MDSF hosts an international symposia that attracts hundreds of renowned MDS medical professionals.
- We train healthcare professionals internationally, insuring worldwide consistency of MDS knowledge.
- We provide the pharmaceutical community with critical representation of the MDS patient experience.



MAKING HOPE WORK.

Good things happen not because we hope they will. It takes work. It takes a group with fighting spirit to bring the right people together and harness their energy and passion. A group that is a catalyst for optimism. A group that says no in the face of the incurable. This is what we do at The MDS Foundation. We are the people who make hope work. **Learn more at MDS-Foundation.org**





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.

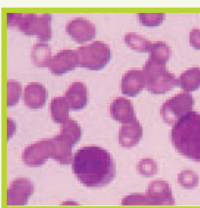
Knowing your subtype, IPSS-M score and gene mutation profile will help facilitate discussions with your healthcare provider on what this means for you personally and help select the best treatment options.

IPSS-M Score

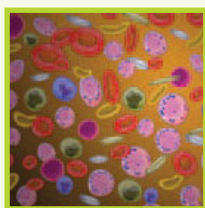
The IPSS-M is a classification system used by doctors to help predict a person's risk of developing AML and overall survival without treatment.

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/>.



Your Life. Your Treatment. Your Way.

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

Did you know that...



You can find an MDS Foundation-certified Center of Excellence near you or anywhere in the country



You can find trials with options that treat your underlying MDS.



You can explore trials that treat the symptoms of your MDS, like anemia.

If you don't know where to start, call us today and we'll get things moving.
(888) 803-1766



Or you can scan this QR code to create your own account and personalize your search.

When did my MDS story begin?

Was it when I first noticed that I could no longer clear the “stingers”, the aerobic bursts of power required to stay on my mountain bike during steep hill climbs? Maybe it was right in front of me during the steady declines in my white blood counts, red counts, and platelets during annual exams? Did it begin when the Blood Disorder Center drilled into my hip bone, and the lab reported MDS-RS-MLD. Maybe it was when my carefully constructed, well-protected sense of personal agency was penetrated by fatigue, breathlessness, and listlessness, and a shattered sense of confidence?



Richard Kimball
Crested Butte, Colorado

No, my MDS story began when I realized that I had brought the “wrong” maps for the steep terrain that lay in front of me.

I had carefully prepared for my retirement and the transition to “my golden years”. I had the resources, the plans, and the energy for life as an elder. But the maps I had drawn and imagined in mid-life were simply inadequate, out of sync, and out of date for this emergent challenge.

I have always been reflective and philosophical about my life. But it was time to go back to the drawing board. The fierce questions that I had always asked myself hadn’t changed, but my answers needed some revision.

I pulled together 12 friends and crafted 12 journals. We would explore 12 different topics with a month to reflect and write on each. Each journal identified a weighty question that one might try to ignore, but that would refuse to go away.

- ① **Who am I now?**
- ② **To what new purposes should I invest my most precious resources—time and energy?**
- ③ **How will I continue to live—joyfully and gratefully—with this enhanced sense of mortality staring me in the face?**
- ④ **How will I embrace and attempt to master the science behind my diagnosis?**
- ⑤ **How can I be the best husband, brother, uncle, and friend that I can possibly be?**
- ⑥ **How am I fooling myself?**

You can learn more about the process at www.fartheron.org.

Borrow it, adapt it, find a way to make it work for you and your circumstances. You can contact me at rokimball@gmail.com for help.

Most of us face personal crises—alone. Thinking alone or in a bell jar. Farther On can open the “conversation” to the thoughts and healing power of others who are facing similar terrain. You must walk your “walk” yourself, but you don’t have to do it alone.

Alone, together.

Richard (Rocky) Kimball is a retired Ph.D. social psychologist, who believes in the healing power of reflection and peer support. He and his wife live in a small cabin at 10,000 feet near Crested Butte, Colorado.



A Life Between the Lines of Blood Counts

Jill's Journey with MDS

Jill Dolgin
Florida

For Jill, the world of labs and clinical protocols was familiar, not just professionally but personally. A doctor of pharmacy with 38 years in oncology, she had overcome cancer twice and lived over two decades cancer-free after her breast cancer treatment in 1996.

In 2020, after a routine blood test related to new statin medication for cholesterol, Jill discovered a noticeable drop in her platelet count. Initially, she dismissed it as a temporary side effect, but despite adjustments and ceasing the medication, her levels continued to decline.

As an oncology pharmacist, Jill remained calm, attributing the anomaly to a potential autoimmune response. It wasn't until her oncologist suggested seeing a hematologist and possibly undergoing a bone marrow biopsy that she began to consider more serious issues. Genetic testing in 2022 indicated the presence of anti-platelet antibodies; however, the hematologist deemed an immediate biopsy unnecessary, so Jill opted for periodic monitoring.

In May 2023, after relocating to Florida, Jill connected with a hematologist at Moffitt Cancer Center. Following continued downticks in her platelet count, she underwent a bone marrow biopsy in February 2024, receiving confirmation of Myelodysplastic Syndrome (MDS). Although she was classified as low-risk for Acute Myeloid Leukemia (AML), the "watch and wait" approach posed a mental challenge for her.

Determined to take action, Jill joined a natural history study for MDS, hoping her contributions could aid future research. She also became involved with the MDS Foundation, a vital source of support and knowledge.

Jill's journey had come full circle—from assisting cancer patients to advocating for herself and others in the MDS community, helping both patients and caregivers take charge of their own care.



Clinical Trials in MDS

New modules coming soon to
[YouAndMDS.com](https://www.YouAndMDS.com)

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





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

TOPICS

Nutrition

Tuesday, February 4, 2025

Other Webinars To Come

**Additional webinars
to be announced!**



FREE ONLINE WEBINAR

**Register today:
[MDS-Foundation.org/events/webinars](https://www.mds-foundation.org/events/webinars)**



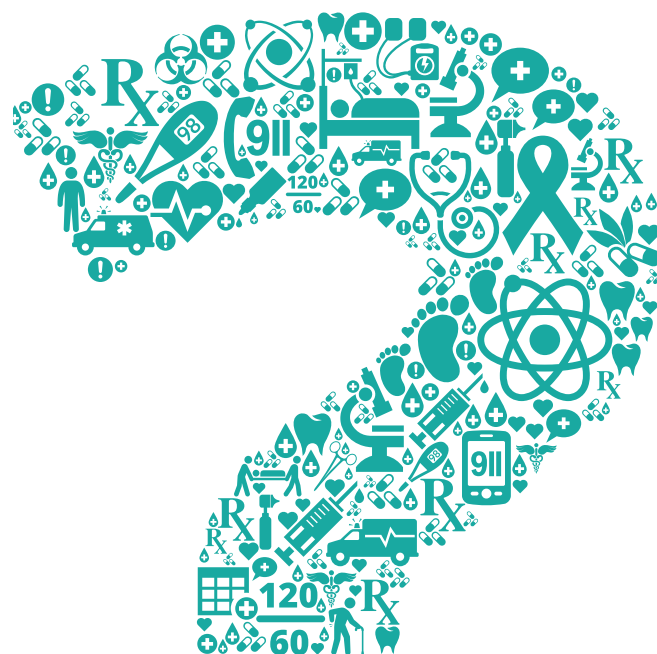
**We are the people
who make hope work.**

Thank you to Abbvie, Bristol-Myers Squibb, Taiho Oncology, and Servier 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



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.

UPCOMING LOCATIONS

- University of Arkansas
 - Emory University
 - City of Hope
 - (2) additional venues to be announced
 - University of Texas Southwestern
 - Rotterdam May 2025 with International Congress
- *Other locations pending*

TOPICS TO BE COVERED

- What is MDS?
- New treatments on the horizon
- Stem cell transplant
- Becoming a Partner in Your Care – presented by MDSF staff

2025
DATES
COMING SOON



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.

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!



COMING IN 2025...

Make sure to visit our website at WWW.MDS-FOUNDATION.ORG for news on upcoming events



WANT TO HAVE A PATIENT FORUM NEAR YOU?

Reach out to our
Director of Patient Care, Ashley
 (Amoncrief@mds-foundation.org),
 to advocate for a forum in
 your community!

UPCOMING MDS PATIENT FORUMS, WEBINAR, PODCASTS & EDUCATIONAL MATERIALS

Based on the 2024 MDSF Patient & Caregiver Survey, the following topics will be the focus of MDSF events, programs, and resources next year:

- Fatigue
- Nutrition
- Caregiver Burnout
- Caregiver Training
- Disease Progression > Myeloid Malignancies Continuum
- Anemia (including transfusion basics)
- Emotional Support: Role of Mental Health Professionals, Starting a Support Group
- Professional Conference Patient Summaries & Clinical Trial News
- Oncologic Emergencies in MDS & Infection Basics
- Impact of MDS on the Whole Body (beyond the marrow)
- Transplant Survivorship
- Common MDS Q&A's



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



THE MDS FOUNDATION MESSAGE BOARD

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

Want to connect with other people who are impacted by MDS? Are you looking for support and understanding that only someone who has traveled down a similar path can provide? Try out the MDS Patient Message Board. The staff at the MDS Foundation work hard to encourage and educate patients, their family members, and caretakers; however, we acknowledge that nothing replaces the comfort that comes from talking to someone who has been there. To date, the MDS Foundation's message board has approximately 2,330 registered users. Join them today by registering for a free account.



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.



30TH
ANNIVERSARY

Turn hope into reality for people with MDS.

In 1994, The Myelodysplastic Syndromes Foundation became the first nonprofit devoted 100% to this unknown blood cancer, and for three decades The MDS Foundation has remained the gold standard for outreach to MDS patients, caregivers and families around the world.

On our 30th anniversary, you can help in achieving our year-end fundraising goals - and take part in a powerful matching fund, thanks to a generous donor, that doubles every dollar you give.

Your donation accelerates MDS research and treatment, expands medical education, and brings critical awareness of MDS to the world. We are the catalyst for progress against a disease that is incurable for so many. Give to our HopeWorks 2024 Fund and turn your hope into a life-changing force.

Every \$1 becomes \$2 when you give now. Give at MDSdonate.org

**DOUBLE YOUR
IMPACT**



**Scan to Donate
MDSdonate.org**



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

The Results Are In!

The MDS Foundation’s Patient and Caregiver Survey was revised and reopened on **February 2, 2024**. Results were reviewed and data was analyzed on **November 7, 2024**. During this time, a total of **232** individuals took part in the survey. Response rates in the past averaged **74** participants per year; thus, 2024 saw a growth of **~214%**. This is likely, in part, due to the use of conditional logic to create a separate question pathway for caregivers.

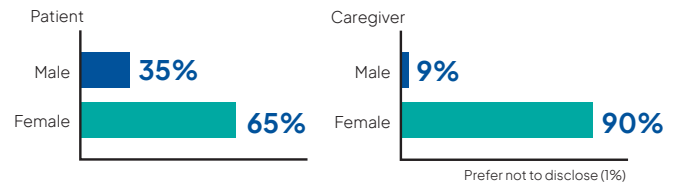
The demographics of the survey were as follows:

Who Took the Survey?

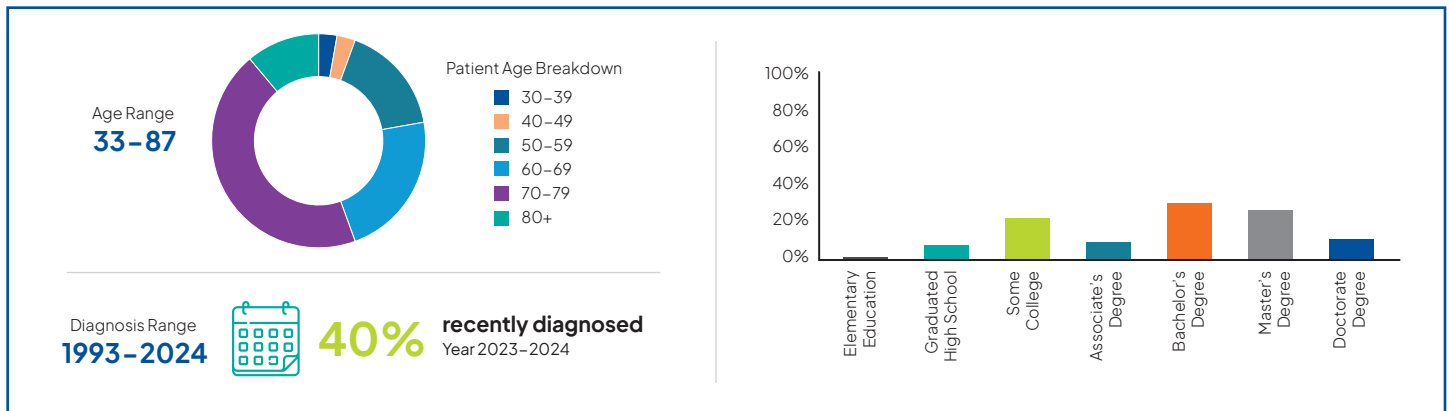
Participant Type



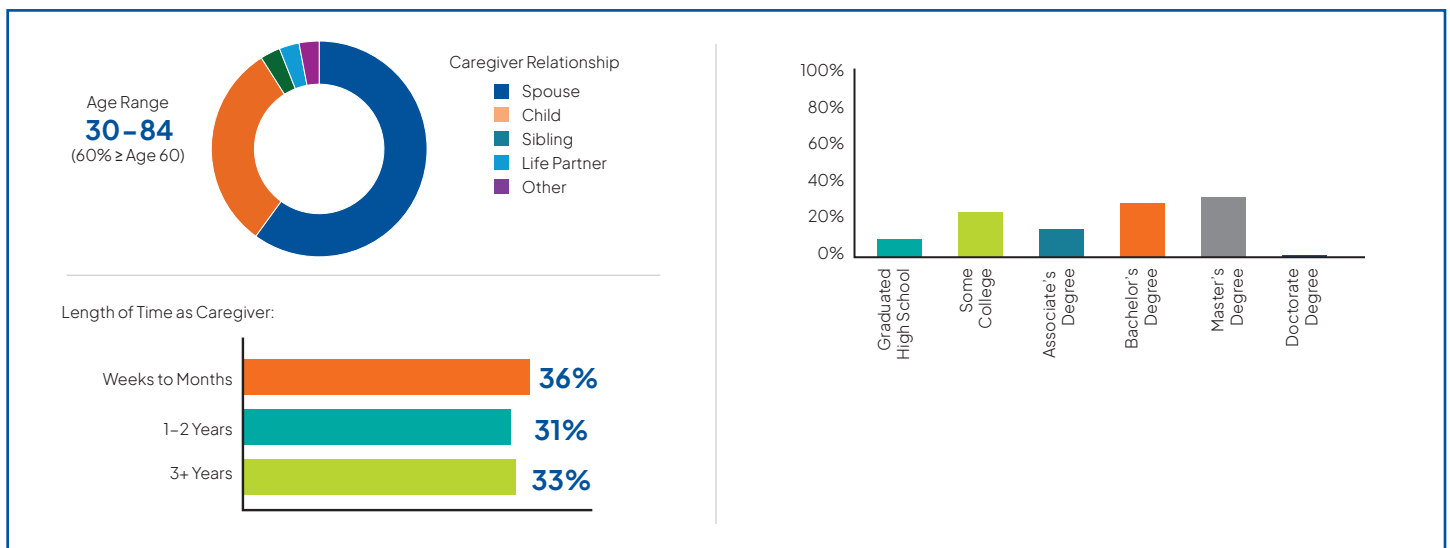
Gender Identification



PATIENTS



CAREGIVERS



What were the Results?

Questions were added this year to gauge the baseline disease knowledge of those completing the survey. It was noted that **60.43%** of patients reported knowing their IPSS-M score and **50.36%** are aware of their IPSS-R score. The majority of patients we serve are lower risk as evidenced by **40.96%** reporting a stratification of low per IPSS-M and **50%** as low per IPSS-R. Most patients, **51.13%**, reported not knowing their subtype. Of those who did, the top three subtypes were as follows: MDS-5q (**35.38%**), MDS-MLD (**16.92%**), MDS-SF3B1 (**10.77%**), and MDS-RS-MLD (**10.77%**). Regarding caregiver knowledge, **55%** reported having all of the information needed to function as a caregiver, while **45%** reported a need to know more about the disease.

Patients were also asked questions regarding diagnosis and treatment. Approximately **74%** of patients felt they were diagnosed in a timely manner. When asked about the timeframe between the onset of symptoms/lab changes and diagnosis, **44%** of respondents reported that signs were present for at least one year prior to receiving a diagnosis. Of note, **13%** of patients reported no symptoms at the time of diagnosis. Approximately **46%** of patients reported visiting a MDS Center of Excellence*; however, **69.92%** reported receiving care primarily with a local hematologist. The most frequently reported visit schedule was once per month (**21.14%** of respondents).

**MDS Centers of Excellence Visted by Survey Respondents: City of Hope, Cleveland Clinic, Columbia, Duke, Emory, Fred Hutchinson, Instituto Nacional de Ciencias Medicas y Nutricion Salvador Zubiran, Johns Hopkins, Mayo Clinic Rochester, Memorial Sloan-Kettering, MD Anderson, Moffitt, Roswell Park, Stanford, University of Alabama, University of California San Diego, UCLA, University of Colorado, University of Florida, University of Iowa, University of Kansas, University of Minnesota, University of Nebraska, University of Pennsylvania, University of Pittsburgh, University of Virginia, Washington University School of Medicine, Yale*

Patients were asked about previous and current treatments for their MDS. Results are as follows:

Treatment Type	Respondents (%)
Watch and wait	55.81%
Blood product transfusion	43.41%
White blood cell growth factors (Neupogen, Zarxio, etc.)	9.30%
Luspatercept (Reblozyl)	11.63%
Erythropoietin stimulating agents (ESAs - Procrit, Aranesp)	34.88%
Iron chelation medications (Exjade, Jadenu)	10.08%
Immunomodulatory drugs (IMiDs - lenalidomide, thalidomide)	13.95%
Hypomethylating agents given through an injection or IV (Decitabine, Vidaza)	23.26%
Hypomethylating agents given by mouth - pill (Inqovi)	3.88%
Immune therapies (anti-thymocyte globulin, Campath)	2.33%
Bone marrow transplant	11.63%
Targeted agents (TIBSOVO)	1.55%
Venetoclax based therapy	4.65%

Questions about clinical trials were included in the survey. While **50.49%** reported considering taking part in a clinical trial, only **13.01%** had been a trial participant. The majority of patients, **72.82%**, reported that their MDS physician had not discussed clinical trials with them. The top three patient identified sources of trial information were the MDS Foundation at **60.50%**, MDS physicians at **33.61%**, and internet searches (Google, Bing, Microsoft Edge, etc.) at **26.05%**.

One of the primary goals of this survey is for the MDS Foundation to determine unmet needs of those impacted by MDS and subsequently use that data for strategic planning purposes. In order to do so, questions centered on how our audience prefers to receive information, where they are going for the information currently, and what content is lacking.

Next Steps:

The MDS Foundation is using the data collected to provide patients and caregivers with relevant and desired resources. Priorities will be developing/improving educational materials and programs, providing emotional support resources, growing awareness of MDS, and offering healthcare provider directed support. Some of the key actions taken include:

- Topics for 2025 MDS Foundation programming have been selected based on the needs identified in the 2024 Patient and Caregiver Survey. Some of the topics which will be covered include: fatigue, nutrition, self-care for caregivers, disease progression, anemia management, and patient level summaries of professional hematology conferences.
- Plans to grow the MDS Centers of Excellence network in 2025 are underway. Two new Centers of Excellence were added in 2024.
- The Foundation has made the fostering of new support groups a priority. Two new groups were started in 2024. A list of patients seeking support groups is being compiled so that patients can be matched to groups with availability.
- MDSF staff are continuing to recruit patients to review educational materials to ensure medical jargon is kept to a minimum.
- Colloquy updates are expected to launch in 2025 which will provide patients with an interactive, online communication tool.
- Campaigns are being developed with the goal of increasing awareness of MDS among primary care physicians and local hematologist/oncologists.

The MDSF Patient and Caregiver Survey will continue to be revised on a yearly basis. The results will serve as the needs assessment for the foundation. The 2025 survey is expected to launch by January 2025.

MDS Foundation Patient and Caregiver Survey

Many of the answers were as expected. For example, **96.49%** of patients and caregivers use smartphones daily. Facebook remains the preferred social media channel with **61.40%** of respondents using the application daily. There was one answer in particular that showed change from previous years. Historically, written material in print was the most desirable information delivery method with **78.41%** selecting this modality in the prior survey. Per the 2024 results, only **26.90%** desired printed information. Written material online came in as the favorite method of information delivery at **41.52%**. When asked where they go for health information, the top three contenders remained consistent with the MDS Foundation at **90.06%**, physicians at **77.19%**, and internet searches at **64.91%**. Of note, participants were allowed to select more than one modality if applicable.

The patients and caregivers were asked what educational resources they would like to see developed for those impacted by MDS. This information was reviewed and categorized as follows:

Category	%	Comments
General MDS Knowledge	49%	<ul style="list-style-type: none"> Less medical jargon Information on prognosis and natural disease course Description and significance of mutations More forums, videos, webinars, and podcasts Presentation of the newest MDS research, developments, and clinical trials Tactics for symptom management, especially fatigue Instruction on how to read and track lab reports Signs and symptoms to report
Emotional Support	29%	<ul style="list-style-type: none"> More support groups, especially in-person New online forums dedicated to communication exchanges between patients/caregivers More patient stories Information on caregiver burnout Creation of a hotline dedicated to MDS
Unsure	18%	<ul style="list-style-type: none"> Reported being new to the MDS space or unfamiliar with current resources available
Physician Directed Support	8%	<ul style="list-style-type: none"> Additional MDS Centers of Excellence in their area Distribution of MDS Foundation resources to local hematologists so they can be given to patients
Lifestyle Modifications	8%	<ul style="list-style-type: none"> Nutrition/dietary recommendations Living with the uncertainty of watch & wait Infection prevention
Financial Resources	2%	<ul style="list-style-type: none"> Co-pay assistance Grants
Homeopathic Therapies	1%	<ul style="list-style-type: none"> Role of vitamins, minerals and herbs in MDS care

Emotional support has consistently been in the top three ongoing unmet needs of both patients and caregivers per prior MDSF Patient and Caregiver Surveys and the MDSF Quarterly Interaction Metrics compiled over the past year. Questions regarding quality of life were asked of both patients and caregivers. Fatigue continues to be an area of concern as **30.17%** of patients report feeling tired upon waking and **34.48%** have difficulty finishing tasks due to fatigue. Approximately one-third of patients reported some psychological impact of the disease; however, it was intermittent with **~30%** reporting feelings of anxiety and/or depression less than once per week. A total of **44.83%** reported feeling hopeful on a daily basis.

It is interesting to note that caregivers reported significant signs of burnout as shown below:

- Exhaustion (emotional and/or physical) - **73.68%**
- Withdrawal from others - **49.12%**
- Loss of interest in things you used to enjoy - **49.12%**
- Feelings of hopelessness or helplessness - **42.11%**
- Eating too much or not eating enough - **54.39%**
- Sleeping too much or too little - **40.35%**
- Trouble concentrating - **43.86%**
- Anger or irritability - **43.86%**
- An increase in physical illness - **15.79%**
- None of the above - **12.28%**

Caregiver Assistance



The majority of caregivers, **71.67%**, reported providing assistance to the MDS patient in their lives on a daily basis. A breakdown of caretaking activities is listed below. The fact that **95%** of caregivers are the source of emotional support for the patients may be contributing to the high rate of caregiver burnout reported.

Patient & Caregiver Survey 2024



Results are in for 2024



Check back in January 2025
for our new survey!

GET READY TO TAKE THE SURVEY IN 2025

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.



PLEASE SCAN TO RECEIVE YOUR GUIDE



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

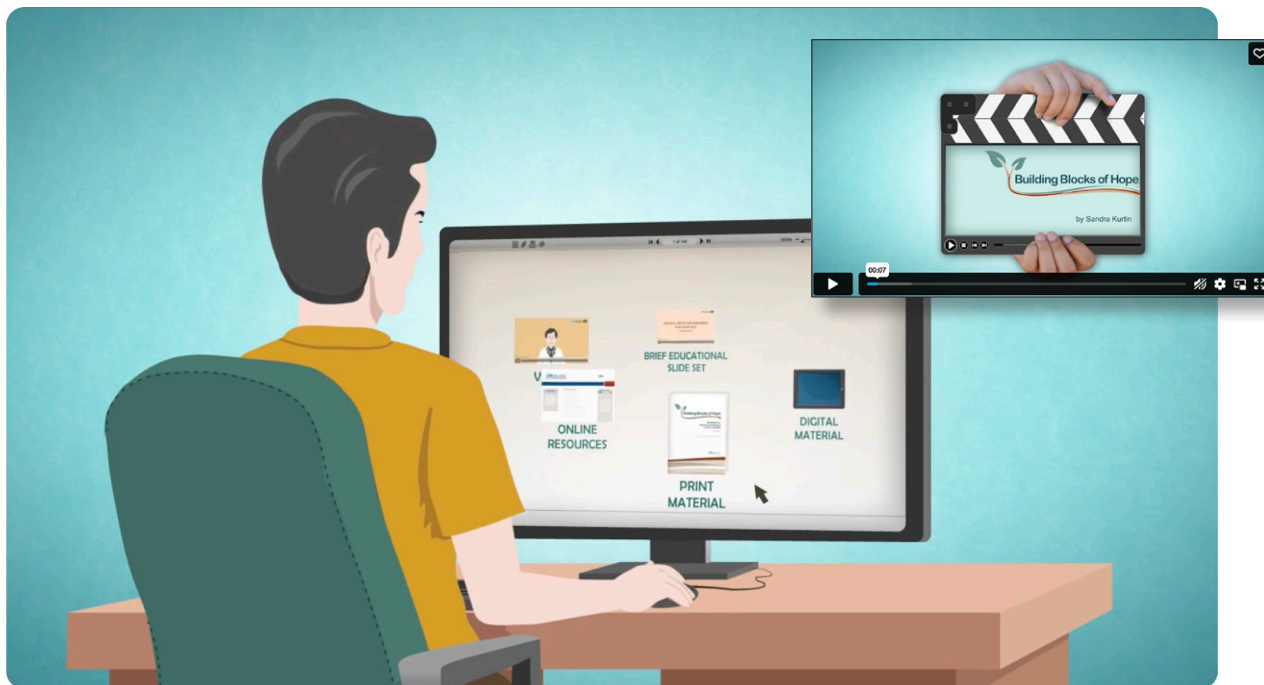
GUIDE TO ASSISTANCE PROGRAMS IN THE UNITED STATES

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)

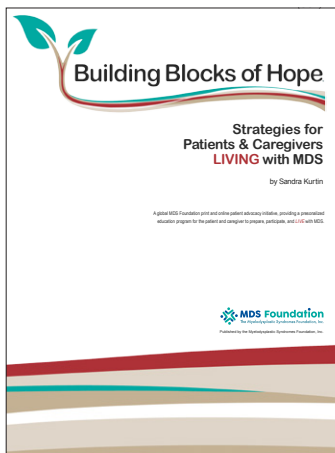
PATIENT RESOURCE

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



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

 Bristol Myers Squibb[®]

 Bristol Myers Squibb[®]

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2007-US-2400375 10/24



 SHARE TO INSPIRE

FARON | BEXMAB

Discover New Possibilities Living With MDS

The purpose of this MDS study is to evaluate a study drug that may help improve the immune response and overall treatment outcomes for patients with MDS when combined with standard chemotherapy (azacitidine).




MDS Study Eligibility Criteria

You may be able to participate in this MDS clinical study if you:

- Are 18 years of age or older
- Have been diagnosed with higher-risk MDS (Higher risk includes intermediate-, high-, or very high- risk MDS)
- Or, have been diagnosed with MDS and previously treated with a hypomethylating agent such as Azacitidine (Vidaza) or Decitabine (Dacogen or Inqovi)

Interested in learning more? Here are some next steps:

 studies@patientwing.com

 (213) 459-2979

 mdsstudy.com

Scan Me!





COMING SOON:

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.**



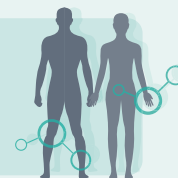
Module 1

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



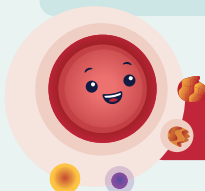
Module 5

Treatment of AML

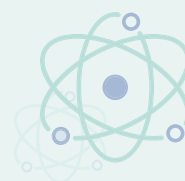


Module 6

Patient empowerment



LAUNCHING IN EARLY 2025



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

mdsJOE.com



SCAN ME



#mdsJOE

MDS JOE is brought to you by the MDS Foundation

Memory Wall

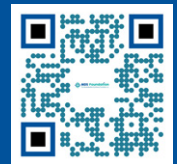
“THE ONES WE LOVE NEVER GO AWAY. THEY WALK BESIDE US EVEN ON THIS DAY. UNSEEN, UNHEARD, YET ALWAYS NEAR. STILL LOVED, STILL MISSED, AND VERY DEAR.”

UNKNOWN



Share a memory online

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



LEAVE YOUR LEGACY – AND CONTINUE TO MAKE HOPE WORK

READY TO BUILD A BETTER FUTURE? A SMALL EFFORT WITH A BIG IMPACT.

Did you know there are ways to support the MDS Foundation that don't affect your current lifestyle or your family's security? You can support the MDS Foundation with gifts that don't impact the way you live — either by designating to receive estate assets in the future — or by making immediate gifts to us of assets that are “out of sight and out of mind.”



Consider the following as ways to Make Hope Work: Will or Trust, Donor Advised Fund, IRA Rollover, Retirement Plan, Stock and Appreciated Assets, Life Insurance.

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

Know AML is the first global education and awareness initiative that provides patients and caregivers with the information, resources, and support they need to deal with acute myeloid leukemia (AML).

know-aml.com

Stay up to date with updates from Know AML through our social channels.

 @KNOW_AML  @KNOWAML

 @knowaml  Know AML



Brought to you by



In collaboration with



All content for Know AML is independently curated by SES in collaboration with ALAN and our ambassador group. Our funders have no influence on the content of Know AML.

Patients with MDS & their relatives / caregivers

The MDS Alliance needs your help and asks for your participation in the

global survey



<https://bit.ly/2024MDSGlobalSurvey>



Are you a MDS patient who has not received treatment?



What is the study?

Akesobio has developed the investigational drug AK117 which may provide a higher response rate than other anti-CD47 antibodies. The purpose of this study is to evaluate the safety and efficacy of AK117 (anti-CD47 antibody) or placebo plus approved Azacitidine in participants with intermediate to very high International Prognostic Scoring System Revised (IPSS-R) myelodysplastic syndrome (MDS).

What are the results?

- Results from Phase 1 trials show lower incidence of anemia, higher response rate and rapid improvement of hemoglobin.
- Previous participants have achieved complete remission for 2+ years.

Participants must:

- be older than 18
- have no prior treatment
- be higher-risk (IPSS-R score of 3.5 or higher)



How to Enroll

To determine if you are eligible and to find a participating center near you, **scan the QR Code, visit sparkcures.com and search for AK117-205**, or call Ashley Moncrief RN, BSN with the MDS Foundation **1-800-637-0839 ext. 210**.

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!



CancerSupportCommunity.org/Registry

JOIN THE REGISTRY



**CANCER SUPPORT
COMMUNITY**
COMMUNITY IS STRONGER THAN CANCER



MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

We need more options for myelodysplastic neoplasms/syndromes (MDS)



About the RENEW Study:

The RENEW Study (NCT06499285) is evaluating an experimental study drug (elritercept) to see if it may safely and effectively reduce the need for blood transfusions due to myelodysplastic neoplasms/syndromes (MDS)-related anemia.

This trial involves at least 20 visits, some of which may be done from home.

During the trial, you will have a 2 in 3 (67%) chance of receiving the active study drug and a 1 in 3 (33%) chance of receiving a placebo. A placebo is an inactive material that looks like the study drug but does not contain any active study drug.

The study drug is expected to block a protein in the blood that interferes with your body's ability to make red blood cells. It will be given by subcutaneous (under the skin) injection about every 4 weeks at the study site.

You may be eligible to participate in RENEW if you*:

- Are over 18 years old
- Have been diagnosed with very low-, low-, or intermediate-risk MDS
- Have anemia that must be treated with blood transfusions
- Are no longer benefitting from the initial treatment you received for MDS, or are not expected to benefit from standard treatment

*You may not be eligible to participate if you have received certain approved treatments for your MDS. The study team will discuss additional criteria with you.





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](https://www.BMSClinicalTrials.com/ELEMENTMDS).

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37354 21OCT2024

CA056-025_Half Page Ad_V1_29May2024_US_ENG

ELEMENT-MDS
First Line NTD



A new research opportunity for Myelodysplastic Syndromes (MDS)

The MAXILUS Study is now enrolling adults who have low or intermediate risk MDS who receive red blood cell transfusions, and you may be able to take part. Researchers are evaluating if the investigational study drug may potentially help reduce the need for blood transfusions in the future.

Compensation for time and travel may be available.



To learn more, scan the QR code or visit [BMSClinicalTrials.com/MAXILUSMDS](https://www.BMSClinicalTrials.com/MAXILUSMDS).

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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

- Creation of a directory of professional members (accessible only to paid members)
- Professional member discussion board (accessible only to paid members) NEW benefit in 2025!
- 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 trials platform

MEMBERSHIP FEES

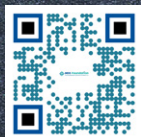
- Student membership (new rate) - \$50
- Student membership + Leukemia Research subscription - \$190
- Professional membership - \$125
- Professional membership + Leukemia Research subscription - \$265



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!



- New anemia trials in LR-MDS (N. Papadantonakis)
- ASH 2023 – HR MDS (N. Papadantonakis)
- Treatment for LR-MDS (U. Platzbecker)
- Treatment for HR-MDS and SCT (N. Kröger)

www.mds-foundation.org/professional/resources/podcasts



WELCOME TO MDS 2025

The 18th International Congress on Myelodysplastic Syndromes (MDS 2025) will take place from **7-10 May 2025** in **Rotterdam, Netherlands**.

Join the premier forum for the latest advancements in myelodysplastic syndromes, where international MDS experts and peers dive into the most recent discoveries, basic and translational research & MDS diagnosis, prognosis, and management.

Benefit from high-level research & science, while getting the chance to meet the global MDS community.

Together, we can enhance knowledge, establish collaborations, and move our field forward.

We look forward to seeing you in Rotterdam!

Dr. Saskia Langemeije
Prof. Arjan van de Loosdrecht
Prof. Theo de Witte
Congress Co-Chairs

REGISTER NOW!



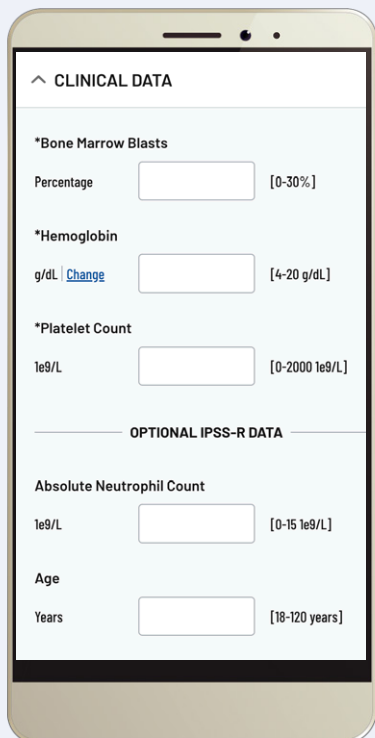
ABSTRACT SUBMISSION DEADLINE:
14 JANUARY 2025

EARLY REGISTRATION DEADLINE:
11 MARCH 2025



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).



^ CLINICAL DATA

*Bone Marrow Blasts

Percentage [0-30%]

*Hemoglobin

g/dL [Change](#) [4-20 g/dL]

*Platelet Count

1e9/L [0-2000 1e9/L]

OPTIONAL IPSS-R DATA

Absolute Neutrophil Count

1e9/L [0-15 1e9/L]

Age

Years [18-120 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

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

ARIZONA

Mayo Clinic Hospital
Phoenix, Arizona
Cecilia Arana Yi, MD/James Slack, MD

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

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

**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
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/Mikhael Sekeres, MD, MS

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

MDS Foundation Centers of Excellence

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

*Jesus Gonzalez Lugo***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 (now Corewell Health)**

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/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**

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***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/Eytan M. Stein***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

MDS Foundation Centers of Excellence

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
Jaroslav 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
Jason M. Melear, MD

University of Texas, MD Anderson Cancer Center
Houston, Texas
Guillermo Garcia-Manero, MD
Hagop Kantarjian, MD

University of Texas, Southwestern Medical Center
Dallas, Texas
Robert H. Collins, Jr., MD, FACP
Yazan Madanat, MD

UTAH

University of Utah Huntsman Cancer Institute
Salt Lake City, Utah
Afaf Osman, MD
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Washington, D.C.
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MDS Foundation Centers of Excellence

SPOTLIGHT ON UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES

The MDS Foundation would like to recognize the Winthrop P. Rockefeller Cancer Institute at the University of Arkansas for Medical Sciences (UAMS). UAMS officially became the first MDS Center of Excellence in Arkansas on July 24, 2024. We are so excited to be able to recommend their services to MDS patients in their area.

GET TO KNOW THE STAFF AT UNIVERSITY OF ARKANSAS MEDICAL SCIENCES



MUTHU VEERA KUMARAN, MD, MPH, FACP

Associate Professor

Director, Hematology Section

Clinical Program Director, Stem Cell Transplantation and Cellular Therapy

BACKGROUND

I was born and raised in Madras, currently called Chennai in South India. I did my medical school at Stanley Medical College in Madras and then moved to US. I earned my master's in public health (MPH) from the University of Oklahoma Health Sciences Center, OKC. Then moved to Philly to do my IM residency from Abington Memorial Hospital, Abington, PA.

I did Transfusion Medicine Fellowship at University of Arkansas Medical Center before my Hematology/Oncology training at Karmanos Cancer Center, Detroit, MI. This was followed by BMT Fellowship at Stanford University, CA.

I joined UAMS as an assistant professor and I am currently serving as the Hematology Section Chief, Program Director of the Stem Cell Transplant and Cellular Therapy and Associate Professor within the Division of Hematology/Oncology.

WHAT INSPIRED YOU TO GO INTO THE FIELD OF HEMATOLOGY?

The science behind hematological malignancies and transplant are fascinating as the field strives to find the Holy Grail of these diseases. The field is so dynamic with cutting edge research and game changing treatments. There is never a dull moment in field of Hematology.

HOW HAVE YOU BEEN INVOLVED WITH THE MDS FOUNDATION?

Being a new member with MDS Foundation we are quick to learn the benefits from this collaboration.

Our collaboration emboldens the focus on MDS patients to offer a comprehensive work up as well as treatment options. They offer previews of the new MDS trials in pipeline and I am able to interact with peers having similar focus across the nation.

MDS Foundation provided us educational materials such as brochures/booklets written in plain and simple language which could empower MDS patients with knowledge and understanding of this complex disease.

We plan to host a MDS Patient and Caregiver Forum in 2025 in collaboration with MDS Foundation to educate/spread awareness about MDS, caregiver role and treatment options.

GET TO KNOW THE STAFF AT UNIVERSITY OF ARKANSAS MEDICAL SCIENCES



ANKUR VARMA, MD, MPH, FACP

*Associate Professor of Medicine
Section of Bone Marrow Transplant and Cell Therapy
Division of Hematology, Oncology*

BACKGROUND

I did my medical school in India (RG Kar Medical college), residency at University of Texas at Houston, Hematology Oncology fellowship at Baylor College of Medicine and my stem cell transplant and cellular therapy fellowship at MD Anderson Cancer Center.

I currently work as an Associate Professor at the University of Arkansas for Medical Sciences. I am also the Associate Program Director for the Hematology Oncology Fellowship at University of Arkansas for Medical Sciences.

WHAT INSPIRED YOU TO GO INTO THE FIELD OF HEMATOLOGY?

Back in medical school, I had developed a deep interest in blood disorders and after my clinical rotation in hematology, I was very clear in my mind that this is what I wanted to do in my life. The opportunity to make a significant impact on patients' lives, the complexity of these blood disorders, and the advancements in research and technology drove me towards hematology. Additionally, the chance to work on innovative treatments and collaborate with multidisciplinary teams is incredibly appealing to me.

HOW HAVE YOU BEEN INVOLVED WITH THE MDS FOUNDATION?

As a part of being a MDS Center of Excellence, I have continued to participate in MDS research, raised awareness about it, and supported patients and their families who are going through this process. These activities have helped advance research, improve patient care, and foster a supportive community for those affected by MDS.

DO YOU HAVE ANY ADVICE FOR OUR READERS?

Here are some helpful pieces of advice for individuals living with myelodysplastic syndrome (MDS) that I encourage my patients to do:

1. **Stay Informed:** Understanding your condition can empower you. Research MDS, treatment options, and clinical trials.
2. **Communicate with Your Healthcare Team:** Open dialogue with your doctors is crucial. Don't hesitate to ask questions or express concerns about your treatment plan.
3. **Monitor Symptoms:** Keep track of any changes in your health, and report them to your healthcare team promptly.
4. **Seek Support:** Connect with support groups, either online or in-person. Sharing experiences with others who understand can be incredibly comforting.
5. **Maintain a Healthy Lifestyle:** Focus on a balanced diet, regular exercise (as advised by your doctor), and adequate rest to help manage your overall well-being.
6. **Manage Stress:** Explore relaxation techniques like mindfulness, meditation, or yoga to help reduce stress.
7. **Stay Engaged:** Participate in advocacy or awareness initiatives. Engaging with the community can provide a sense of purpose and connection.



MDS Foundation Centers of Excellence

SPOTLIGHT ON VANDERBILT UNIVERSITY MEDICAL CENTER

The MDS Foundation would like to recognize staff at Vanderbilt University Medical Center (VUMC).

Kathryn Kennedy, ACNP-BC was selected for the MDS Foundation Nurse Leadership Board in October 2024. Her experience and expertise have brought value to our organization, and we look forward to working with her.

GET TO KNOW THE STAFF AT VANDERBILT UNIVERSITY MEDICAL CENTER



KATE KENNEDY, MSN, APRN, ACNP-BC, AOCNP

*Hematology/Oncology
Vanderbilt University Medical Center*

BACKGROUND

Education:

BSN- University of SC (2004)

MSN Vanderbilt University (2010)

Current Title:

ACNP-BC, Team Lead for Outpatient Hematology APPs at
Vanderbilt Ingram Cancer Center

HOW HAVE YOU BEEN INVOLVED WITH THE MDS FOUNDATION?

I've participated in walks and fundraising as well as spoken at one of the conferences. I also direct a lot of patients to the MDSF website.

WHAT INSPIRED YOU TO GO INTO THE FIELD OF HEMATOLOGY?

My uncle had cancer when I was a teenager which is how I wound up in oncology nursing. My first job out of nursing school happened to be on a generally hematology focused floor at New York Presbyterian-Weill Cornell and I loved it. I loved that different than most inpatient nursing, I got to form a real relationship with the patients. I also enjoyed the acute nature of the disease. I never wanted to do anything else. Now that I am more established in my career, I continue to enjoy the relationships with patients but also enjoy how quickly the field is evolving – there is always something new to learn!

DO YOU HAVE ANY ADVICE FOR OUR READERS?

My best advice is to ask all of the questions you can think of. Make notes and bring that to your appointment to review with your provider. Include disease questions, treatment questions and symptom management questions. If you don't feel like you're getting good answers, seek a second opinion. (Second opinions are never a bad idea!)

Why Register?

Join the touch online community for **FREE** access

1,200+ medical professionals registering every month
 100's of whom have earned accreditations and have seen an average increase in knowledge and competence of +19% from
 5,000+ hours of education delivered by 500+ global medical professionals.



With Sincere Thanks

We want to take a moment to acknowledge our dedicated industry partners and say **THANK YOU** for your relentless support of **The MDS Foundation** and for playing a critical role in finding a cure for every individual affected by MDS.



This publication is provided to you on behalf of the MDS Foundation with generous contributions from Taiho Pharmaceutical and AbbVie Inc.

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 ~January 17, 2025.

Q2:2024

Centers of Excellence Referrals

Cedars-Sinai (1); Dartmouth-Hitchcock (1); Fox Chase-Temple University (1); John Theurer Cancer Center at Hackensack (1); Indiana University (1); Johns Hopkins (1); King Faisal Specialist Hospital & Research Centre (Saudi Arabia) (1); Monash Health (Australia) (1); University of Chicago Medical Center (1); University of Texas Southwestern (1); Yale (1)

Total Referrals: 11 (11.45% 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	41 (42.71%)
Looking for educational resources	13 (13.54%)
Discussed clinical trials & SparkCures	8 (8.33%)
Needing financial resources	10 (10.42%)
Questions requiring provider input	3 (3.13%)
Seeking emotional support	12 (12.5%)
Fundraising/donations/volunteers	6 (6.25%)
Seeking information on webinars/forums/events	2 (2.08%)

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

04/20/2024 – 07/19/2024

No. of unique patients/caregivers who called in:

44

No. of unique patients/caregivers who emailed:

39

Message boards answered: **10**

AS OF 07/19/24:

Assisted **96** different patients/caregivers/friends in 13 weeks (~7.38 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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have been requested in the following locations:

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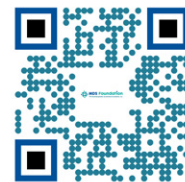
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