

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

Highlights Included in This Issue

PATIENTS & FAMILIES SECTION

- 2 From the Foundation
- 3 Move for MDS 2024
- 8 Our Patient Stories
- 10 MDS Patient Events
- 16 2024 Patient and Caregiver Survey Results
- 22 Journey of Empowerment (JOE)

PROFESSIONAL SECTION

Meeting Highlights & Announcements

- 30 18th International Congress on MDS

Research

- 31 MDS Risk Assessment Tools
- 32 MDS Centers of Excellence
- 41 Our Pharmaceutical Partners
- 42 MDSF Quarterly Interactive Metrics
- 43 MDS Foundation Leadership

Dear Friends,

Tracey Iraca
The MDS Foundation



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.

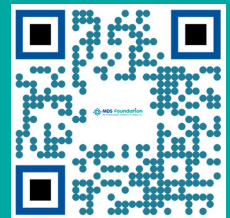
At The MDS Foundation, we're the people who make hope work, and when you join the Move for MDS, you take the first step in joining a team dedicated to leaving an imprint on MDS and every single person it touches.



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](https://www.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](https://www.mds-foundation.org)**

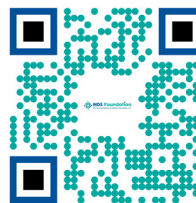




Visit Our Microsite

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.

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

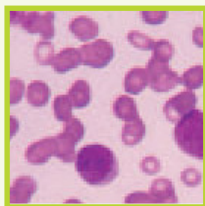


Do you know...

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.

IPSS-M Score

MDS Subtype



Bone Marrow Blast

Mutation Profile

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 Spark**Cures** 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.

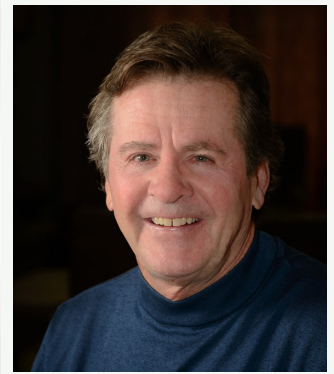
If you don't know where to start, call us today and we'll get things moving.
(888) 803-1766



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**



**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



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



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!



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

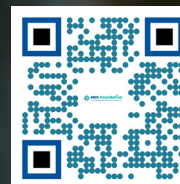


THE MDS FOUNDATION MESSAGE BOARD

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.





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.**

WWW.MDS-FOUNDATION.ORG

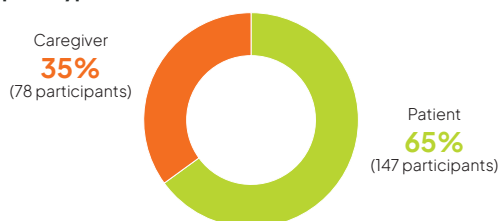
The Results Are In!

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.

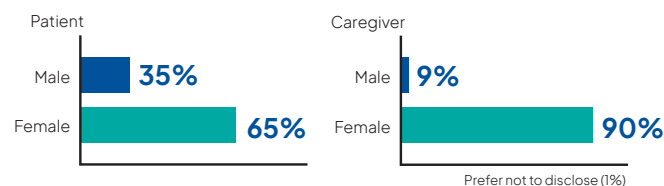
The demographics of the survey were as follows:

Who Took the Survey?

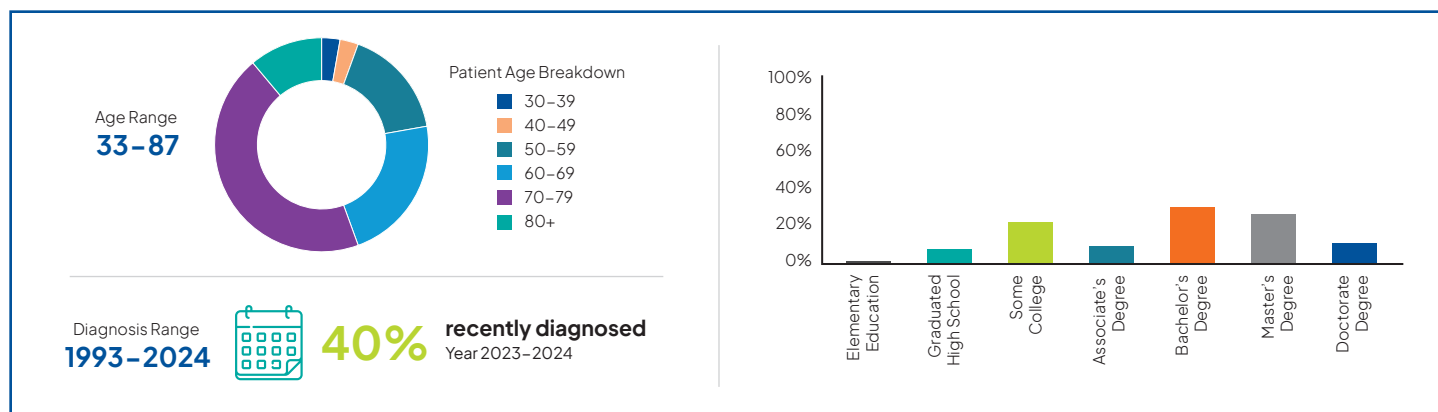
Participant Type



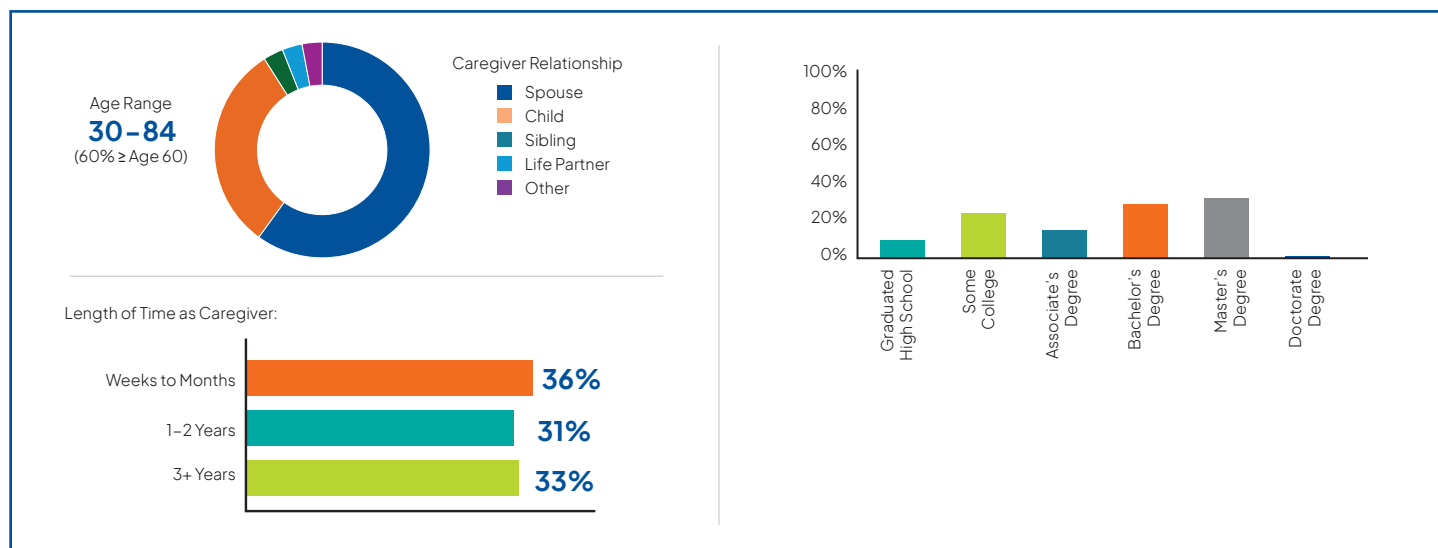
Gender Identification



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:

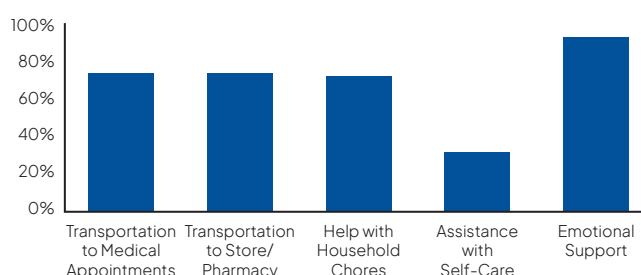
Category	%	Comments
General MDS Knowledge	49%	<ul style="list-style-type: none"> • Less medical jargon • Information on prognosis and natural disease course • Description and significance of mutations • More forums, videos, webinars, and podcasts • Presentation of the newest MDS research, developments, 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

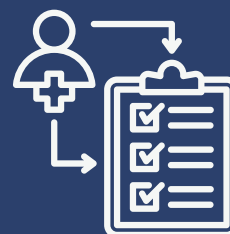


The majority of caregivers, **71.67%**, reported providing assistance to the MDS patient in their lives on a daily basis. A breakdown of caretaking activities is listed below. The fact that **95%** of caregivers are the source of emotional support for the patients may be contributing to the high rate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

Patient & Caregiver Survey 2024



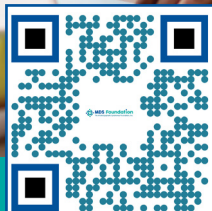
Results are in for 2024



**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


MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

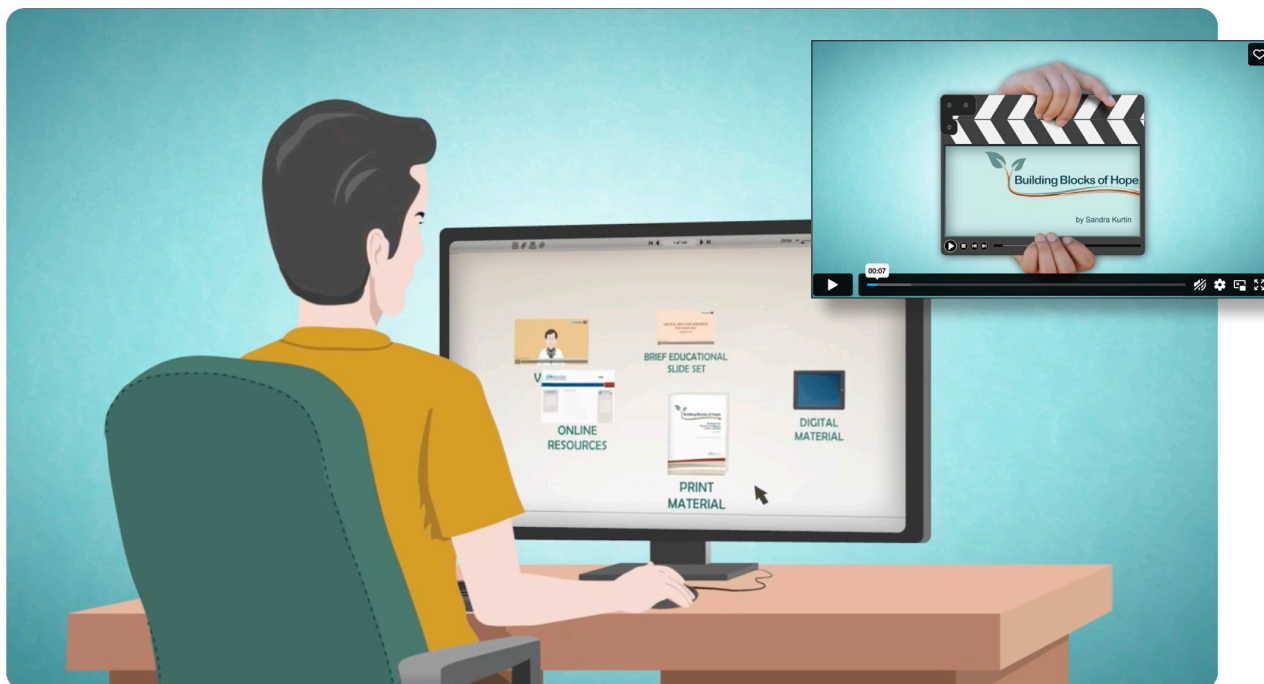
GUIDE TO ASSISTANCE PROGRAMS IN THE UNITED STATES

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)

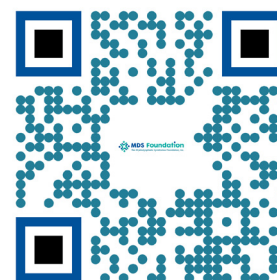
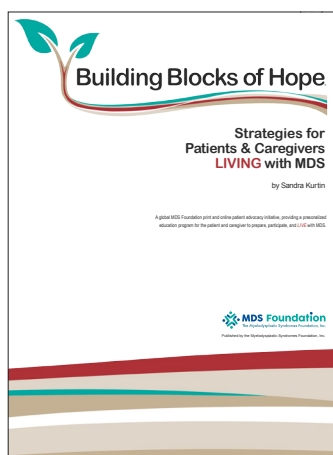
PATIENT RESOURCE

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®

© 2024 Bristol-Myers Squibb Company.
REBLOZYL® is a trademark of Celgene Corporation, a Bristol Myers Squibb company.
REBLOZYL® is licensed from Merck & Co., Inc., Rahway, NJ, USA and its affiliates.
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

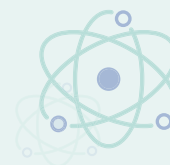
 (213) 459-2979

 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.**



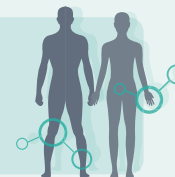
Module 1

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



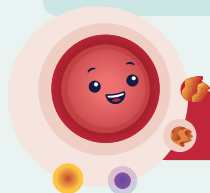
Module 5

Treatment of AML



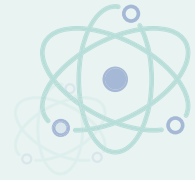
Module 6

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

 **MDS Foundation**
The Myelodysplastic Syndromes Foundation, Inc.



#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.

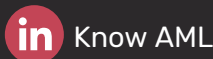
Contact Tanya Rhodes, Director of Development, to learn more and to discuss the difference you can make.
trhodes@mds-foundation.org or 609-298-1600 x205

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.



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>



MDS
Patient Study

ENROLL NOW

Search AK117-205 at
SparkCures.com

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)



A clinical trial for people with MDS
and anemia is coming soon

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).

©2024 Bristol-Myers Squibb Company.
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).

©2024 Bristol-Myers Squibb Company.
37355 21OCT2024

CA056-1060_Half Page Ad_V1_14May2024_US_ENG

PROFESSIONAL SECTION

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

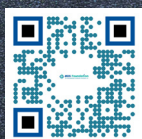
- Student membership (new rate) - \$50
- Student membership + Leukemia Research subscription - \$190
- Professional membership - \$125
- Professional membership + Leukemia Research subscription - \$265



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 Langemeijde
Prof. Arjan van de Loosdrecht
Prof. Theo de Witte
Congress Co-Chairs

REGISTER NOW!



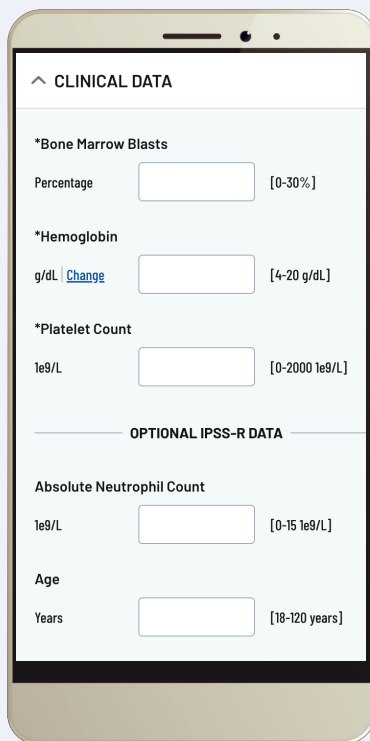
ABSTRACT SUBMISSION DEADLINE:
14 JANUARY 2025

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. Litrow, 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

**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. Sanikomm, 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
Paul J. Shami, MD

VIRGINIA

University of Virginia
Charlottesville, Virginia
Michael Keng, MD

WASHINGTON

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

WASHINGTON, DC

**Georgetown University Hospital
Lombardi Comprehensive Cancer Center**
Washington, D.C.
Catherine Broome, MD

**George Washington University,
VA Medical Center**
Washington, D.C.
Anita Aggarwal, DO

WISCONSIN

**Medical College of Wisconsin
Hematologic Malignancies Program**
Milwaukee, Wisconsin
Ehab Atallah, MD

**University of Wisconsin,
Madison Medical School**
Madison, Wisconsin
Ryan Mattison, MD

INTERNATIONAL

ARGENTINA

Sanatorio Sagrado del Corazón
Buenos Aires, Argentina
Marcelo Iastrebnier, MD

ARMENIA

**Blood Disorders Center of Armenia,
Hematology Center after R. Yeolyan**
Yerevan, Armenia
Anna Sevoyan, MD
Gevorg Tamamyanyan, MD, MSc, PhD, DSc

AUSTRALIA

Cabrini Haematology & Oncology Centre
Melbourne, Australia
Melita Kenealy, MD/Gary Richardson, MD

Monash Health Monash University
Clayton, Victoria, Australia
Jake Shortt, BMedSc, MBChB
FRACP FRCPA PhD

**Peter MacCallum Cancer Institute
University of Melbourne**
East Melbourne, Australia
John F. Seymour, MD

Royal Hobart Hospital
Tasmania, Australia
Rosemary Harrup, MD

The Royal Melbourne Hospital
Parkville, Victoria, Australia
David Ritchie, MD

MDS Foundation Centers of Excellence

AUSTRIA

**Hanusch Hospital
Medical University of Vienna**

Vienna, Austria
Michael Pfeilstöcker, MD

University Hospital of Innsbruck

Innsbruck, Austria
Reinhard Stauder, MD

BELGIUM

AZ Sint-Jan AV

Brugge, Belgium
Dominik Selleslag, MD

University Hospital Leuven

Leuven, Belgium
Michel Delforge, MD, PhD

BRAZIL

AC Camargo Hospital–Cancer Center

São Paulo, Brazil
Luiz Fernando Lopes, MD, PhD

**Hospital das clínicas da Faculdade de
Medicina da Universidade de São Paulo**

São Paulo, Brazil
Elvira D. Rodrigues Pereira Velloso, MD, PhD

Universidade Federal de Ceará

Ceará, Brazil
Silvia Maria M. Magalhães, MD, PhD

Universidade Federal de São Paulo

São Paulo, Brazil

Hospital Israelita Albert Einstein

São Paulo, Brazil
Nelson Hamerschlag, MD, PhD
Pereira Velloso, MD, PhD
Elvira D. Rodrigues Pereira Velloso, MD, PhD

CANADA

Princess Margaret Hospital

Toronto, Ontario, Canada
Karen Yee, MD

**Odette Cancer Centre
Sunnybrook Health Sciences Center**

Toronto, Ontario, Canada
Rena Buckstein, MD, FRCP
Richard A. Wells, MD

St. Paul's Hospital

Vancouver, British Columbia, Canada
Heather Leitch, MD, PhD

**University of Toronto Hospital
for Sick Children**

Toronto, Ontario, Canada
Yigal Dror, MD

CHINA

**Guangdong General Hospital &
Guangdong Academy of Medical Sciences**

Guangzhou, China
Xin Du, MD, PhD

**Institute of Hematology and
Blood Diseases Hospital
Chinese Academy of Medical Sciences**

Tianjin, China
Zhijian Xiao, MD

**The First Affiliated Hospital of
Soochow University, Jiangsu Institute
of Hematology**

Jiangsu Province, China
Suning Chen, MD, PhD

**The First Affiliated Hospital of
Zhejiang University**

Zhejiang Province, China
Hongyan Tong, MD, PhD

**The Sixth Hospital Affiliated to
Shanghai Jiaotong University**

Shanghai, China
Chunkang Chang, MD, PhD

CROATIA

Clinical Hospital Merkur

Zagreb, Croatia
Inga Mandac Ragulj, MD

CZECH REPUBLIC

**Institute of Hematology &
Blood Transfusion**

Prague, Czech Republic
Jaroslav Cermák, MD, PhD

DENMARK

**Odense University Hospital
The University of Southern Denmark**

Odense, Denmark
Klas Raaschou-Jensen, MD
Claus Marcher, MD

Rigshospitalet National University Hospital

Copenhagen, Denmark
Kirsten Grønbaek, MD
Lars Kjeldsen, MD, PhD

FRANCE

**Centre Henri Becquerel
Rouen University School of Medicine**

Rouen, France
Aspasia Stamatoullas, MD

**Centre Hospitalier Universitaire (CHU)
de Angers Service des Maladies du Sang**

Angers, France
Norbert Ifrah, MD

**Centre Hospitalier Universitaire (CHU)
de Grenoble**

Grenoble, France
Jean-Yves Cahn, MD

**Centre Hospitalier Universitaire
(CHU) de Limoges Hôpital Dupuytren**

Limoges, France
Pascal Turlure, MD

**Centre Hospitalier Universitaire (CHU)
de Nancy**

Nancy, France
Agnès Guerci-Bresler, MD, PhD

**Centre Hospitalier Universitaire
(CHU) de Tours – Bretonneau**

Tours, France
Emmanuel Gyan, MD, PhD

Hôpital Cochin/University Paris V

Paris, France
Francois Dreyfus, MD

Hôpital Saint Louis/University Paris VII

Paris, France
Pierre Fenaux, MD, PhD
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

Georg-August-Universität Göttingen

Göttingen, Germany
Detlef Haase, MD, PhD

**Hannover Medical School
Medizinische Hochschule Hannover**

Hannover, Germany
Matthias Eder, MD, PhD

**Heinrich-Heine Universität Düsseldorf
University Hospital**

Düsseldorf, Germany
Ulrich Germing, MD

**Johannes Gutenberg University
Medical Center Mainz**

Mainz, Germany
Markus Radsak, MD, PhD

Johann Wolfgang Goethe Universität

Frankfurt Main, Germany

Gesine Bug, MD

Klinikum Rechts der Isar

Technical University of Munich

Munich, Germany

Katharina Götze, MD

MLL Münchner Leukämielabor

Munich, Germany

Torsten Haferlach, MD

Wolfgang Kern, MD

Rems-Murr-Klinik Winnenden

Winnenden, Germany

Prof. Dr. med Markus Schaich, MD

St. Johannes Hospital

Heinrich-Heine Universität

Duisburg, Germany

Carlo Aul, MD, PhD

Aristotle Giagounidis, MD, PhD

Albert-Ludwigs-Universität Freiburg

Freiburg, Germany

Michael Lübbert, MD, PhD

Universität Hamburg

Hamburg, Germany

Nicolaus Kröger, MD, PhD

Universitätsklinikum Carl Gustav Carus

Dresden, Germany

Katja Sockel, MD

University Children's Hospital

Freiburg, Germany

Charlotte Niemeyer, MD

University of Cologne

Cologne, Germany

Karl-Anton Kreuzer, MD

University Hospital Essen

Dept. for Hematology and Stem Cell

Transplantation

Essen, Germany

Thomas Schroeder, MD

University Hospital Leipzig

Leipzig, Germany

Uwe Platzbecker, MD

University Hospital Mannheim

Mannheim, Germany

Wolf-Karsten Hofmann, MD

GREECE

Patras University Hospital

Patras, Greece

Argiris Symeonidis, MD

University of Athens Laikon Hospital

Athens, Greece

Panagiotis Diamantopoulos MD, PhD

University Hospital of Alexandroupolis

Alexandroupolis, Greece

Dr. Ioannis Kotsianidis

University General Hospital Attikon

Athens, Greece

Vassiliki Pappa, MD

HUNGARY

Semmelweis University

School of Medicine

Budapest, Hungary

Judit Várkonyi, MD, PhD

INDIA

Tata Medical Centre

Kolkata, India

Col (Dr.) Deepak Kumar Mishra, MD

Tata Memorial Hospital

Mumbai, India

Manju Sengar, MD

IRELAND

Adelaide and Meath Hospital

Dublin, Ireland

Helen Enright, MD

ISRAEL

Tel-Aviv Sourasky Medical Center

Tel-Aviv, Israel

Moshe Mittelman, MD

Chaim Sheba Medical Center

Tel Hashomer, Israel

Drorit Grizim Merkel, MD

ITALY

**Cancer Center – IRCCS Humanitas
Research Hospital**

Milan, Italy

Matteo G. Della Porta, MD

Centro di Riferimento

Oncologico di Basilicata (CROB)

Rionero in Vulture (PZ), Italy

Pellegrino Musto, MD

Istituto di Ematologia

Università' Cattolica Sacro Cuore

Rome, Italy

Giuseppe Leone, MD

Policlinico Universitario di Roma

Tor Vergata

Rome, Italy

Sergio Amadori, MD

Maria Teresa Voso, MD

S. Eugenio Hospital Tor Vergata University

Rome, Italy

Pasquale Niscola, MD

University of Florence Azienda

OSP Careggi

Florence, Italy

Valeria Santini, MD

University of Pavia School of Medicine

Fondazione IRCCS Policlinico San Matteo

Pavia, Italy

Mario Cazzola, MD

JAPAN

Kyoto University Hospital

Kyoto, Japan

Akifumi Takaori, MD

**Metropolitan Research and Treatment
Center for Blood Disorders**

(MRTC Japan)

Tokyo, Japan

Kiyoyuki Ogata, MD, FACP

Nagasaki University Hospital

School of Medicine,

Atomic Bomb Disease Institute

Nagasaki City, Japan

Yasushi Miyazaki, MD

Saitama Medical University

International Medical Center

Hidaka, Saitama, Japan

Tomoya Maeda, MD, PhD

Tokyo Medical College

Tokyo, Japan

Kazuma Ohyashiki, MD, PhD

MEXICO

Instituto Nacional de Ciencias

Medicas y Nutrición Salvador Zubiran

American-British-Cowdray

Cancer Center

Mexico City, Mexico

Alvaro Aguayo, MD

THE NETHERLANDS

Radboud University

Nijmegen Medical Center

Nijmegen, The Netherlands

Saskia M.C. Langemeijer, MD

Vrije Universiteit Medical Center

Amsterdam, The Netherlands

Arjan A. van de Loosdrecht, MD, PhD

NORWAY

Haukeland University Hospital

Bergen, Norway

Astrid Olsnes Kittang, MD, PhD

MDS Foundation Centers of Excellence

POLAND

**Jagiellonian University
Collegium Medicum**
Kraków, Poland
Aleksander Skotnicki, MD, PhD

Medical University of Warsaw
Warsaw, Poland
Krzysztof Madry, MD

PORTUGAL

Hospital de Santa Maria
Lisbon, Portugal
Joao F. Lacerda, MD

SAUDI ARABIA

**King Faisal Specialist Hospital &
Research Centre**
Riyadh, Saudi Arabia
Amr Hanbali, MD

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

SINGAPORE

Singapore General Hospital
Aloysius Ho, MD

SOUTH AFRICA

**University of Cape Town
Groote Schuur Hospital**
Cape Town, South Africa
Nicolas Novitzky, MD, PhD

SOUTH KOREA

**Catholic Blood and Marrow
Transplantation Center
The Catholic University of Korea**
Seoul, Korea
Yoo-Jin Kim, MD

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

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

SPAIN

Hospital Universitario de Salamanca
Salamanca, Spain
Maria Diez-Campelo, MD, PhD

Hospital Universitario La Fe
Valencia, Spain
Guillermo F. Sanz, MD, PhD

**Vall d'Hebron Institute of Oncology
University Hospital Vall d'Hebron**
Barcelona, Spain
David Valcárcel, MD, PhD

SWEDEN

**Karolinska Institute at
Karolinska University Hospital Huddinge**
Stockholm, Sweden
Eva Hellström-Lindberg, MD, PhD

SWITZERLAND

Basel University Hospital
Basel, Switzerland
Jakob R. Passweg, MD, MS

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

St. Claraspital AG
Basel, Switzerland
Stefani Parmentier, MD

TAIWAN

**Chang Gung Memorial Hospital
Chang Gung University**
Taoyuan, Taiwan
Lee-Yung Shih, MD

National Taiwan University Hospital
Taipei, Taiwan
*Hwei-Fang Tien, MD, PhD
Wen-Chien Chou*

THAILAND

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

TUNISIA

Hospital Aziza Othmana
Tunis, Tunisia
Balkis Meddeb, MD

TURKEY

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

UKRAINE

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

UNITED KINGDOM

**Aberdeen Royal Infirmary
Aberdeen University School of Medicine**
Foresterhill, Aberdeen, Scotland
Dominic Culligan, MD

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

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

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

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

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

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

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

University Hospital of Wales
Cardiff, Wales
Jonathan Kell, MD

VIETNAM

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



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.


Practical articles


Expert Interviews


News and insights

 **touch™
ONCOLOGY**

 **touch™
HAEMATOLOGY**



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)

SUPPORT GROUPS

have been requested in
the following locations:

ARIZONA • CALIFORNIA •
FLORIDA • OREGON • ZAMBIA

MDS Foundation Leadership

Board of Directors

Pierre Fenaux, MD

Hôpital St Louis, Université de Paris 7

Peter L. Greenberg, MD

Stanford University School of Medicine

Tracey Iraca

The MDS Foundation, Inc.

Sandra E. Kurtin, PhD, ANP-C, AOCN

The University of Arizona Cancer Center

Luca Malcovati, MD

University of Pavia Fondazione IRCCS
Policlinico San Matteo

Stephen D. Nimer, MD, Chair

Sylvester Comprehensive Cancer Center

Michael R. Savona, MD

Vanderbilt University School of Medicine

MEMBERS EMERITUS

John M. Bennett, MD

University of Rochester Medical Center

Eva Hellström-Lindberg, MD, PhD

Karolinska Institute at Karolinska University
Hospital Huddinge

Charlotte M. Niemeyer, MD

University Children's Hospital

Medical and Scientific Advisory Board

Rafael Bejar, MD, PhD

Moore's Cancer Center at the
University of California, San Diego

Rena Buckstein, MD

Sunnybrook Health Sciences Centre

Mario Cazzola, MD

University of Pavia Fondazione IRCCS
Policlinico San Matteo

Jane Churpek, MD

UW Carbone Cancer Center
University of Wisconsin
School of Medicine and Public Health

Theo J.M. de Witte, MD, PhD

Radboud University Nijmegen Medical Centre
Nijmegen Centre of Molecular Life Sciences

Erin P. Demakos, RN, CCRN

Icahn School of Medicine at Mount Sinai

Benjamin Ebert, MD, PhD

Dana-Farber Cancer Institute

Silvia M. M. Magalhães, MD, PhD

Federal University of Ceará
Hospital Universitário Walter Cantídio

Moshe Mittelman, MD, Chair

Tel-Aviv Sourasky Medical Center

Yasushi Miyazaki, MD

Nagasaki University
Graduate School of Biomedical Sciences
Atomic Bomb Disease Institute

Ghulam J. Mufti, DM, FRCP, FRCPATH

King's College London & King's College
Hospital

Seishi Ogawa, MD, PhD

Kyoto University

Uwe Platzbecker, MD

University Hospital Leipzig

Guillermo Sanz, MD

Hospital Universitario y Politécnico La Fe

Akiko Shimamura, MD, PhD

Boston Children's Cancer and
Blood Disorders Center

Lewis R. Silverman, MD

Icahn School of Medicine at Mount Sinai

International Nurse Leadership Board

Erik Aerts, RN, President HNHCP

Zürich, Switzerland

Angelika Bitter, Dresden, Germany

Mariela Andrea Blanco,

Nursing Graduate, Magister

Buenos Aires, Argentina

Claudia Boglione, RN, Florence, Italy

Jordan Hwang Chung Cheng, RN, MN,

ADV. Dip. (Oncology Nursing)

Singapore

Nicole Crisp, RN, BScN, MN, NP-adult

Edmonton, Alberta, Canada

Erin Demakos, RN, CCRN

New York, New York, United States

Rebecca Dring, RN,

Masters of Advanced Nursing Practice
Melbourne, Australia

Lenn Fechter, RN

Stanford, California, United States

Janet Hayden, RN, BSc(hons), MPH

London, United Kingdom

Amelia Hodson, AG-ACNP

Charlottesville, Virginia, United States

Miki Iizuka, RN,

Tokyo, Japan

Jacqueline Jagger, BA, RN, MN

Gosford, Australia

Natasha L. Johnson, MS, APRN, AOCNP

Tampa, Florida, United States

Kate Kennedy, MSN, APRN,

ACNP-BC, AOCNP

Vanderbilt University Medical Center

Sandra E. Kurtin, PhD, ANP-C, AOCN

Tucson, Arizona, United States

Officers

Stephen D. Nimer, MD, Chair

Tracey Iraca, Executive Director

Sandra E. Kurtin, PhD, ANP-C, AOCN,

Treasurer

Lea Harrison, Secretary

Development Board

Deborah Peirce, Chair

Talent/Leadership and Organizational
Development Executive, MDS Caregiver

Stuart Goldberg, MD

MDS Specialist

Jennifer Keam, MD, MPH

MDS Caregiver

Julia McGuire, Advisor

Executive Vice President,
Campbell & Company
Madeleine's Mom, MDS Patient

Lindsay Wilde, MD

MDS Specialist

Jim Williams

MDS Survivor and
Health Care Entrepreneur

Petra Lindroos Kolqvist, RN

Goteborg, Sweden

Ashley Moncrief, RN, BSN

Nashville, Tennessee, United States

Cindy Murray, RN, MN, NP-adult

Toronto, Ontario, Canada

Geke Ong, RN, London, United Kingdom

Phyllis Paterson, RN, RSCN, Dip. Onc.

Cambridge, United Kingdom

Samantha Soggee, RN, MN

Geelong, Victoria, Australia

Amber Thomassen, AGPCNP-BC, AOCNP

Miami, Florida, United States

Sara M. Tinsley, PhD, APRN, AOCN

Tampa, Florida, United States

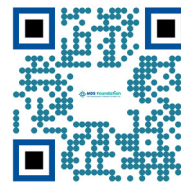
Catherine Vassili, NP, MN

Victoria, Australia

Advancing Research & Patient Care

The 18th International Congress on
**Myelodysplastic
Syndromes**

Rotterdam, The Netherlands
7–10 May 2025



Join international MDS experts to learn about the latest advances, discoveries, basic and translational research, and MDS diagnosis, prognosis, and management.