SEE PAGE 24 FOR PROFESSIONAL SECTION

MDS Foundation

VOLUME 30 ISSUE 1
SPRING/SUMMER 2024

NEWSLETTER

The Myelodysplastic Syndromes Foundation, Inc.

Move FOR MDS

Community Walks to Drive Awareness & Accelerate Research

TAKE AN IMPORTANT STEP AHEAD

2024 is off to a great start – join us for our Fall walk events!

PLAN TO ATTEND

BREAKFAST SYMPOSIUM AT ASH

San Diego, California

In This Issue

PATIENTS & FAMILIES SECTION

PROFESSIONAL SECTION

Meeting Highlights & Announcements

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.

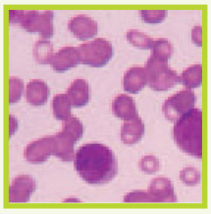
Knowing your subtype, IPSS-M score and gene mutation profile will help facilitate discussions with your healthcare provider on what this means for you personally and help select the best treatment options.

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.

KNOWLEDGE IS POWER

Visit Our Microsite

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

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

John M. Bennett, MD

First Chair and Founding Member of the MDS Foundation

To learn more, visit our website at https://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.

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

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

Move FOR MDS

Community Walks to Drive Awareness & Accelerate Research

Now you can take these important steps to move MDS research ahead!

THANK YOU TO OUR SPRING WALKERS!

TAMPA
April 7

NASHVILLE
May 5

SAVE THE DATE FOR OUR FALL EVENTS:

CHICAGO
August 25 – Burnham Park

NEW YORK CITY
September 22 – Battery Park City

BOSTON/GLOBAL
October 20 – Boston Common

Scan to register

MoveForMDS.org

Every Move for MDS walk is more than a way to raise the funds that allow The MDS Foundation to do its critical work. It's also a healthy day of outdoor family activity with lots of ways to have a good time: From yard games and caricature artists to photobooths, kid-friendly activities and more.

At The MDS Foundation, we're the people who make hope work. And when you participate in the Move for MDS movement, so are you. It's the walk you can do any way that suits you – and know that you're making a difference for those impacted by this rare blood cancer, and helping doctors and researchers come closer to a cure.

3

WAYS TO JOIN THE MOVE FOR MDS MOVEMENT:

1. **Participate in person:** MoveforMDS.org
2. **Participate virtually** if you can't do the walk or be there in person: MDSvirtual.org
3. **Simply donate**: MDSdonate.org

WHEN YOU WALK WITH US, THE CURE FOR MDS IS A LOT CLOSER.

Dear Supporter:

We look forward to seeing you at an upcoming Move for MDS, our 5k community walks to drive awareness for Myelodysplastic Syndromes.

Take a moment now to join the Move for MDS movement and support the mission of The MDS Foundation. Your donation is what drives everything we do for MDS. (And by the way, you can still participate in the movement even if you can't make the date or you're unable to walk. We'll explain shortly.)

Put hope to work by turning it into action.

MDS is a rare and challenging blood cancer that is still incurable for some. But that's only until there is a treatment. And that day is coming.

At The MDS Foundation, we believe it's not enough to just hope for a cure. Because hope works best when you combine it with action. For 30 years, The MDS Foundation has been a global non-profit dedicated to helping MDS patients, families and caregivers, and to accelerating research and therapies for Myelodysplastic Syndromes and its related diseases.

As the gold standard in outreach and education among both the patient and healthcare professional community, The MDS Foundation offers patient support, support groups, live patient forums and webinars, ongoing medical education, and the best attended seminars, symposia and conferences in the industry.

When is a walk not just a walk?

Every Move for MDS walk is more than a way to raise the funds that allow The MDS Foundation to do its critical work. It's also a healthy day of outdoor family activity with lots of ways to have a good time: From yard games and caricature artists to photobooths, kid-friendly activities and more.

If you've been to past Move for MDS events, you know that they are close-knit celebrations of community. Each one is an opportunity to meet, share ideas, ask questions and take courage from people who are all in the same boat. It's an invaluable way to learn about local Centers of Excellence, where to get help, and strategies for care and living.

What if you can't make it? Or don't feel like walking?

Not to worry. If you can't make the date of the event or you're physically unable to participate in a 5k walk, you can participate anywhere and anytime that's good for you simply by joining the Virtual Move for MDS.

The beauty of a virtual walk is that you can do it day or night, on the day of the local event or before. Walk solo, walk with a team of friends or family, walk with your regular walking group – however, whenever and wherever you're most comfortable.

Join right now.

At The MDS Foundation, we're the people who make hope work. And when you participate in the Move for MDS movement, so are you. It's the walk you can do any way that suits you – and know that you're making a difference for those impacted by this rare blood cancer, and helping doctors and researchers come closer to a cure.

Sincerely,

Madelyn Geltch, *Development and Communications Manager*

Tanya Rhodes, *Director of Development*

SparkCures

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

Know Your Treatment Options

Using the NEW MDS Clinical Trial Matching Finder

Powered by Spark**Cures**

The National Comprehensive Cancer Network (NCCN) is an organization that provides doctors with treatment guidelines for 97% of all cancers. Their MDS guidelines state that "the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged."

But did you know that through a 2023 study of MDS patients, we found that clinical trials were NEVER discussed with nearly 75% of the patients surveyed?

The MDS Foundation is committed to helping you understand your options. That's why we 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 trial is an ongoing process. 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.

Even if a trial isn't suitable now, staying informed about clinical research is crucial. The worst time to search for a trial is when you urgently need one.

Start your journey today by creating your free account: https://mdsf.sparkcures.com/signup

Patient Stories

My MDS Journey

Ann Chouinard
Traverse City, Michigan

I'm Ann and this is my MDS Journey. My story begins with the initial diagnosis of MDS 5Q Deletion, January 2020, and continues to my bone marrow transplant, May 2024. The videos include a series of recordings intended to help others navigate their experience with MDS and stresses how to advocate for yourself. Each video offers tips I learned throughout each stage of the disease. My journey went from low risk MDS to high Risk MDS in four years. Future videos will include my transplant experience. The videos are not intended to give medical advice, the videos are from a patient's perspective.

Thank you to the MDS Foundation for creating a safe place where we can come together as a supportive community.

Feel free to add your experiences or ideas in the comments below the videos. Thank you for watching!

Blessings...

A VIDEO SERIES:
Please scan the QR code to access Ann's Patient Story

Each Day is Different

I went to Kaiser for basic lab tests, I was feeling great at the time. They detected something that needed further extensive lab tests and wanted a bone marrow biopsy.

Tina Agulair
Los Angeles, CA

My MDS journey began in February of 2021. The next thing I know, they are sending me to an oncologist. Wait a minute I thought, an oncologist, isn't that a cancer doctor? The oncologist tells me the news, I have MDS/blood cancer. The fear sets in. The family is now aware of my diagnosis. The tears begin.

I begin different medications, then shots, then numerous rounds of chemotherapy. By August 2021, I have become extremely weak. I have a hard time breathing and now need a wheelchair to get around. I am 53 years old, what is happening to me? My life was great with lots of fun, sun and activities. Nothing has worked so far. I begin needing up to 10 blood and platelet. transfusions a week. Everything that was going into my body would be gone the next day and I would have to do it all over again. My body wasn't taking anything in, and I felt as though I was becoming a daily a pin cushion. The tears were many and the frustration was high. My days were filled with sitting in the transfusion chairs at the hospital. My oncologist tells me there is nothing more he can do for me by January of 2022; my only option is a Bone Marrow Transplant at the City of Hope.

Immediately Kaiser contacts the City of Hope. City of Hope contacts Be the Match and by May of 2022 after doing extensive testing to qualify for the Bone Marrow Transplant, they find a match. I don't even know how I passed all the tests as weak as I was. I can't believe it, a 19-year-old female donor out of Europe is my 100% match. Prayers Answered. It was hard being in the hospital 2 months straight after the transplant, but I was determined to live. I missed my husband John, my son Johnathan, my daughter-in-law Chelsea, my sister Anita, my father Fred and other extended family and friends. The transplant worked for me and Thank God I am alive today.

Fast forward to 2023 and 2024. I do continue to have several graft vs host disease issues from the transplant, and I struggle with this daily. I thought after doing the transplant I would be good to go. Not quite, I have no taste buds, swelling in the mouth, severe eye issues affecting my sight and I still have weakness at times. Each day is different. I have good and bad days, but I fight through them as best I can with my team of doctors, medication and the support of my family. I am alive and that is what matters. In July of 2023, my husband and I welcomed our first grandchild, Ethan. My reason for living. My utter joy in life. I knew I was on this earth for a reason.

Along with my team of doctors from Kaiser to the Los Angeles Bone Marrow Transplant Team, to Ophthalmology, to Optometry, to the CT scan and MRI teams, to the Laboratory, to the MDS Foundation, they have all been instrumental in my success and health through this journey.

Whenever I need direction or help or information for support the MDS Foundation is always there to guide me. I am forever grateful and thankful for all that have participated in my continued success of being alive and getting better. Thank you and God Bless!!!!!!!!

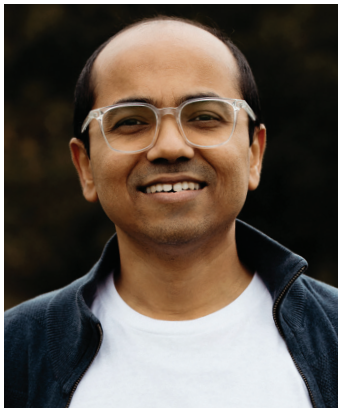
MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

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**

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

UPCOMING 2024 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.

- We have planned a comprehensive series of webinars for 2024 bringing experts and the MDS community together to provide educational information, best practices, tools, and resources.
- Whether you are a newly diagnosed patient, a long-term survivor, or caregiver, our webinar series will have something for you.
- We will be collaborating with renowned hematology professionals who will be addressing key topics and questions you may have using language that is easy to understand in a 90–minute format that will include live Q&A opportunities for all participants.
- Register now for our webinars planned for this series. Led by top thought leaders in the field, you can be assured you are getting information you can trust.

Caring For The Caregiver

Thursday, July 18, 2024

Updates on MDS Classifications

Saturday, August 3, 2024

MDS Foundation: Who We Are and What We Do!

Thursday, October 10, 2024

FREE ONLINE WEBINAR

Register today:
MDS-Foundation.org/webinar

Thank you to Abbvie, Bristol-Myers Squibb, Taiho Oncology, and Servier for supporting these important events.

Hope doesn't work just by wishing. That's important to know for fighting MDS, a challenging but little-known cancer that, left undetected, can progress to acute myeloid leukemia and other forms of blood cancer. MDS is not incurable. It simply hasn't been cured yet. But with your help, that day is coming.

Your donation turns hope into reality. For 30 years, The Myelodysplastic Syndromes Foundation has been a catalyst for progress: Supporting patients. Expanding education. Accelerating research. Bringing critical awareness of MDS to the world. We depend on your investment to make this progress happen. Donate today. And make hope a life-changing force. **Give at MDSdonate.org**

Scan to Donate
MDSdonate.org

We are the people who make hope work.

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The Myelodysplastic Syndromes Foundation, Inc.

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

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.

JUNE 29TH, 2024: SAN DIEGO, CA

Moores Cancer Center at UC San Diego Health, Goldberg Auditorium, Second Floor, San Diego, California, USA

SEPTEMBER 14, 2024: DENVER, CO

University of Colorado Anshutz Medical Campus, Aurora, Colorado, USA

OCTOBER 5TH, 2024: NEW HAVEN, CT

Yale Cancer Center Smilow Auditorium – 2nd Floor, New Haven, Connecticut, USA

NOVEMBER 2, 2024: BIRMINGHAM, AL

University of Alabama at Birmingham, Wallace Tumor Institute, Conference Room 101, Birmingham, Alabama, USA

SEPTEMBER 7, 2024: HOUSTON, TX

The University of Texas MD Anderson Cancer Center

REGISTRATION IS REQUIRED

DON'T MISS OUT ON THESE INFORMATIVE, FREE 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 spot in your community!

JOE IS GETTING AN UPGRADE!

JOE in MDS, short for '**J**ourney **O**f **E**mpowerment', launched in March 2023. Since then, we have listened to the insights provided by patients, caregivers, and healthcare professionals to improve the platform and enhance the learner experience.

We will be making updates to **JOE in MDS** throughout 2024, aligning the platform with the feedback we received from the MDS community.

- New modules (including nutritional information)
- Improving user experience
- Content updates
- More visuals and diagrams
- Resource section
- Tailored learning
- Updated dashboard
- New quiz questions

VISIT TODAY

mdsJOE.com

SCAN ME

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

JOE

#mdsJOE

MDS JOE is brought to you by the MDS Foundation

PLEASE SCAN TO RECEIVE YOUR GUIDE

GUIDE TO ASSISTANCE PROGRAMS IN THE UNITED STATES

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

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 SES

In collaboration with ALAN

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.

ARE YOU RECEIVING TREATMENT FOR A BLOOD CANCER DIAGNOSIS AND STRUGGLING WITH POOR SLEEP?

We are looking for US-based adults with a blood cancer diagnosis to enroll in a 20-week remote study of an app-based wellness intervention

Participation involves:

- Completing online surveys
- Wearing a sleep device on index finger and tracking nightly sleep
- Providing 3 blood samples at a nearby lab
- Being randomized to use one of two wellness apps
- Using wellness app 10-minutes per day for 8-weeks

Participants will be compensated for completing study-related measures

To learn more and find out if you are eligible:
Scan the QR code →
or Visit → https://redcap.link/hemescreening

The Heme Study is an NIH-funded study being conducted through the Mays Cancer Center at the University of Texas Health Sciences Center at San Antonio, led by Dr. Ruben Mesa and Dr. Jennifer Huberty (BRANY IRB #21-136-583)

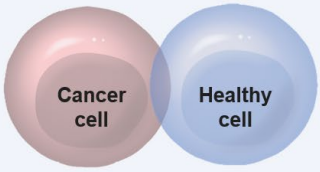
Questions? Email us at hemestudy@uthscsa.edu

Novel clinical trial for high-risk, CD33-positive AML or MDS

VOR

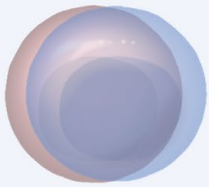
The VBP101 clinical trial aims to shield your healthy blood cells while enabling the use of powerful therapies to target any remaining cancer cells following your Hematopoietic Cell Transplant (HCT)

Biology: Overlapping Targets



Cancer cells and healthy cells have similar surface targets

Problem: Unwanted Toxicity

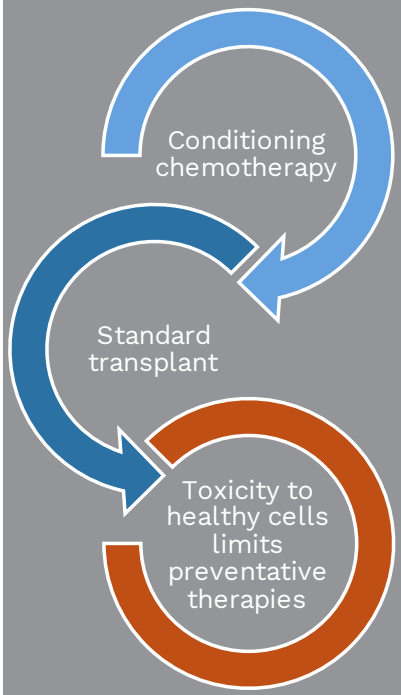


The overlapping targets limit treatment opportunities due to toxicity to healthy cells

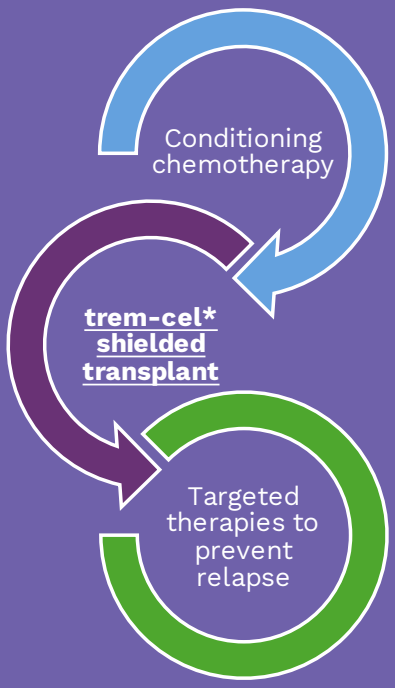
Solution: Shielded Transplants

Vor Bio utilizes shielded transplants to protect healthy cells and to allow therapies to be cancer-specific

Standard transplant



Our investigational shielded transplant



Inclusion Criteria

- Patients with high-risk, CD33+ acute myeloid leukemia (AML) or myelodysplastic syndrome (MDS)
- Age ≥18 and ≤70 years
- Must have a matched related or unrelated stem cell donor

Exclusion Criteria

- Prior autologous or allogeneic stem cell transplantation
- Prior treatment with Mylotarg™ (gemtuzumab ozogamicin) in the past 3.5 months
- Active central nervous system (CNS) leukemia

*trem-cel is an investigational CD34-selected, CD33-deleted hematopoietic stem cell product that can potentially shield healthy donor cells from CD33-targeted therapies.

Travel support available for study participants

Learn more

Are you living with AML or MDS and interested in a cutting-edge clinical trial?

If you have acute myeloid leukemia (AML) or higher-risk myelodysplastic syndrome (MDS) you may be able to participate in **TakeAim Leukemia**, a clinical study evaluating the oral medication **emavusertib**

Emavusertib is an investigational medication that was designed to block proteins that trigger cancer growth in AML and MDS. Blocking these proteins (called IRAK4 and FLT3) may help stop or slow cancer growth.

The goal of the **TakeAim Leukemia** study is to understand the safety of **emavusertib**, and to measure its effect in treating cancer.

Who can join TakeAim Leukemia?

People **aged 18 and older** and living in **Czechia, France, Germany, Israel, Italy, Poland, Spain, or the United States** can participate in the study.

You **may be able to** take part if:

You have been diagnosed with **AML** or higher-risk **MDS** with certain mutation(s)*

+

You have had prior treatment with 1 to 2 anticancer therapies†

Ask your doctor if you qualify to participate

What to expect in the clinical study

Before	During	After
Your doctor will help you determine whether you can participate	• After an initial visit you will receive the oral medication **emavusertib, taken twice-daily** • You will receive emavusertib at no cost to you • During treatment, you will visit your doctor **2 to 3 times per month for the first 2 months**, then **once every month** or **once every other month**	You will visit your doctor for assessments 1 week and 1 month after finishing treatment and to check on disease status every 3 months thereafter

Travel support available for study participants

*Mutations in *FLT3* or mutations in both *FLT3* and spliceosome factors (*SF3B1* or *U2AF1*)
†For AML with *FLT3* mutations but not spliceosome mutations, prior treatment must have included a FLT3 inhibitor therapy
Some study sites are not yet active. Additional enrollment criteria apply. For additional information and a list of locations where the study is taking place, please visit: https://www.curis.com/study/dose-escalation-expansion-study-of-ca-4948-as-monotherapy-in-patients-with-aml-or-mds/

Reference: ClinicalTrials.gov. Accessed March 25, 2024. https://clinicaltrials.gov/study/NCT04278768

Coming Soon

JOE and AML

Keep an eye out for upcoming announcements!

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

MDS JOE is brought to you by the MDS Foundation

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

MDS Foundation Patient and Caregiver Survey

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

Patient & Caregiver Survey 2024

The MDS Foundation would like to understand more about you (the MDS patient and the MDS caregiver), your health, and your educational and support needs.

PLEASE SCAN THE QR CODE TO BEGIN THE SURVEY.

READY TO TAKE THE SURVEY?

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.

MDS PATIENT & FAMILY PODCAST

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

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

LISTEN ON:

APPLE PODCASTS SPOTIFY CASTBOX

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

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

UNITED STATES

ALABAMA

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

ARIZONA

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

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

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

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

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

COLORADO

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

CONNECTICUT

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

FLORIDA

Blood and Marrow Transplant Center
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/Mikkael Sekeres, MD, MS

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

MDS Foundation Centers of Excellence

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

GEORGIA

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

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

ILLINOIS

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

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

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

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

INDIANA

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

IOWA

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

KANSAS

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

MARYLAND

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

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

MASSACHUSETTS

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

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

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

Tufts Medical Center
Boston, Massachusetts
Andreas Klein, MD

MICHIGAN

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

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

MINNESOTA

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

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

MISSOURI

Washington University School of Medicine Siteman Cancer Center
St. Louis, Missouri
Matt Walter, MD
Meagan Jacoby, 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/Amit Verma, MD

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

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

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

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

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

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

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

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

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

NORTH CAROLINA

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

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

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

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

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

OHIO

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

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

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

PENNSYLVANIA

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

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

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

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

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

TENNESSEE

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

TEXAS

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

Texas Oncology – Austin Midtown
Austin, Texas
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
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

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Milwaukee, Wisconsin
Ehab Atallah, MD

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

INTERNATIONAL

ARGENTINA

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Buenos Aires, Argentina
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ARMENIA

Blood Disorders Center of Armenia, Hematology Center after R. Yeolyan
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Anna Sevoyan, MD

AUSTRALIA

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Melita Kenealy, MD/Gary Richardson, MD

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Clayton, Victoria, Australia
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East Melbourne, Australia
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Royal Hobart Hospital
Tasmania, Australia
Rosemary Harrup, MD

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

MDS Foundation Centers of Excellence

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

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Hanusch Hospital
Medical University of Vienna
Vienna, Austria
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Medical University of Vienna
Vienna, Austria
Peter Valent, MD

University Hospital of Innsbruck
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Reinhard Stauder, MD

BELGIUM

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The Sixth Hospital Affliated to Shanghai Jiaotong University
Shanghai, China
Chunkang Chang, MD, PhD

CROATIA

Clinical Hospital Merkur
Zagreb, Croatia
Inga Mandac Ragulj, MD

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Panagiotis Diamantopoulos MD, PhD

University Hospital of Alexandroupolis
Alexandroupolis, Greece
Dr. Ioannis Kotsianidis

University General Hospital Attikon
Athens, Greece
Vassiliki Pappa, MD

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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

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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

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Maria Teresa Voso, MD

S. Eugenio Hospital Tor Vergata University
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Pasquale Niscola, MD

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Kyoto, Japan
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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

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Mexico City, Mexico
Alvaro Aguayo, MD

THE NETHERLANDS

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

MDS Foundation Centers of Excellence

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

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

NORWAY

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Bergen, Norway
Astrid Olsnes Kittang, MD, PhD

POLAND

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Medical University of Warsaw
Warsaw, Poland
Krzysztof Madry, MD

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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

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

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

SPAIN

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Salamanca, Spain
Maria Diez-Campelo, MD, PhD

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

Vall d'Hebron Institute of Oncology Universitary 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

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 DR. MOSHE MITTELMAN

Moshe Mittelman MD, completed his term as the Chairman, Department of Medicine, at the Tel Aviv Sourasky (Ichilov) Medical Center, in 2020. He continues as a senior consultant for Medicine and Hematology. He is also Professor Emeritus, in medicine and hematology, the School of Medicine, Tel Aviv University.

Among other tasks, Prof. Mittelman serves as the Chief Technology Officer, Scientific-Medical Director and a consultant for a biotech group (TALENT) and investors, and is involved in several biotech start-ups companies. In 2019 he established, and continues to run a hematology-oncology service in the LISOD Oncology Center, in Kiev, Ukraine. He serves as the Chairman, The Scientific Board, the (International) MDS Foundation (From 2021). Since July 2023, Moshe is the Chairman of the Israel Cancer Association.

Professor Mittelman graduated from the Faculty of Medicine, Tel Aviv University in 1976, and completed a residency in Internal Medicine at the Hasharon Hospital, Petah-Tikva, Israel. He later undertook a Combined Clinical and Research Fellowship Programme in hematology and oncology at the George Washington University Medical Center, Washington DC, USA, and The National Institutes of Health (NIH), Bethesda, USA, before returning to Israel in 1989. On returning to Israel, he served as Deputy-Director (1989–1994) and then Director (1994–2003), Department of Medicine B, Hasharon Hospital. In 2003 he moved to Tel-Aviv Sourasky (Ichilov) Medical Center, to serve as the Chief of Medicine A and the Chairman of The Department of Medicine (9 wards, 360 beds), till 2020.

Professor Mittelman's research interests include basic and clinical aspects of stem cell disorders such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN), multiple myeloma, basic and clinical effects of erythropoietin, translational research of malignant hematology and applying digitalization into practical medicine. He published more than 230 professional papers summarizing his clinical and research activities in prestigious journals such as Blood; Haematologica; British Journal of Haematology; American Journal of Hematology; Lancet Haematology, Annals of Hematology; Leukemia; Leukemia Research; Annals of Internal Medicine; Journal of Clinical Oncology, and others. He was a member of the editorial board of European Journal of Internal Medicine, and currently serves in the editorial board of the Israel Medical Association Journal (IMAJ), Journal of Clinical Medicine (also co-editor) and Haematologica, as well as a reviewer for the top journals in hematology, oncology and medicine. Moshe co-authored more than 220 abstracts presented in international meetings.

Over the years Moshe has served in academic and public duties, including Chairman, the admission committee for medical students, TAU; The National Committee for new technologies in public health ("Vaadat Sal"); BOD, Israel Cancer Association (he is currently the chairman); Board of Trustees, The Academic College Tel Aviv-Jaffa; Secretary & Chairman, Israel Society of Internal Medicine; President, Israel Society of Hematology; The national committee for clinical trials (Helsinki), Israel Ministry of Health; The national council of cancer.

GET TO KNOW DR. MITTELMAN

PLEASE PROVIDE SOME DETAILS ABOUT YOUR PROFESSIONAL BACKGROUND SUCH AS WHERE YOU RECEIVED YOUR EDUCATION AND YOUR CURRENT TITLE?

I was born and educated in Israel. I graduated the Tel-Aviv University Medical School and proceeded with residency in internal medicine. Then (1986) I moved to the US, where I underwent hematology-oncology fellowship, at The George Washington University Medical Center and The National Institutes of Health (NIH). I returned to Israel in late 1989, to serve as the vice-chair and later the Director of Medicine at Hasharon-Rabin Medical Center. In 2003 I moved to Tel-Aviv Sourasky Medical Center, an 1300-bed tertiary academic center (one of the two biggest in the country), to become Chairman of Medicine, till 2019. Since then, I have served as a hematology consultant, the Chief of the MDS Center, as well as additional academic, public (Chairman, The Israel Cancer Association) and other duties.

HOW HAVE YOU BEEN INVOLVED WITH THE MDS FOUNDATION?

My relations and involvement with MDSF goes back to the beginning of the organization. As a fellow in the US, my mentor, Dr. Larry Lessin made me fascinated in the topic of MDS. I realized that this was a relatively new and unrecognized field. Patients were really suffering with very little to offer. The potential to study, investigate and eventually help – was unlimited. I started seeing MDS patients and research in the field. In 1991, I attended the 2nd International MDS symposium in Bournmouth, UK, met Dr. John Bennett and Dr. Peter Greenberg, the founders of MDSF, became involved, and the rest is history.

WHAT INSPIRED YOU TO GO INTO THE FIELD OF HEMATOLOGY?

As a young physician, I learned that hematology is one of the few fields that looks at the whole body, all the human biological systems and tries to provide holistic solutions to serious medical problems. I also appreciated that the field is indeed interesting, allows a lot of research and has a potential to help people, thus the decision was easy.

DO YOU HAVE ANY ADVICE FOR OUR READERS?

I am not sure that I have a good advice to wise people. I believe that combining what makes you interested in with a benefit to the public – is supposed to be a win-win situation. For patients and family members I always advise to continue to be optimistic because 1) things are really getting better and there is always something better to look forward 2) research has shown that a "positive thinking" is really associated with better outcomes.

MDS Foundation Centers of Excellence

SPOTLIGHT ON DR. IOANNIS KOTSIANIDIS

CENTER OF EXCELLENCE: UNIVERSITY HOSPITAL OF ALEXANDROUPOLIS

Dr. Kotsianidis serves as PI for the Department of Hematology, University Hospital of Alexandroupolis which was just accepted as a Center of Excellence on April 29, 2024. We are welcoming him and his instruction to the CoE community.

GET TO KNOW DR. KOTSIANIDIS

PLEASE PROVIDE SOME DETAILS ABOUT YOUR PROFESSIONAL BACKGROUND SUCH AS WHERE YOU RECEIVED YOUR EDUCATION AND YOUR CURRENT TITLE?

I am currently a Professor of Hematology at Democritus University of Thrace and the Head of the Hematology department at University Hospital of Alexandroupolis, in Alexandroupolis Greece. I obtained my medical degree from Aristotle University of Thessaloniki and my PhD degree in Hematology from Democritus University of Thrace. After my training in Internal Medicine and Hematology in various hospitals in Greece I worked for 2 years as a clinical research fellow at the laboratory of Professor Irene Roberts and Dr Anastasios Karadimitris in Hammersmith Hospital, Imperial College London.

HOW HAVE YOU BEEN INVOLVED WITH THE MDS FOUNDATION?

I am member of EUMDS and IWG-PM and my clinical and research interests are focused in myeloid neoplasms and in particular MDS, thus I regularly follow the activities of MDSF for many years now.

WHAT INSPIRED YOU TO GO INTO THE FIELD OF HEMATOLOGY?

Actually mathematics was my first love, but my father, a physicist himself, insisted that I should study medicine. However, after I succeeded at our national examinations my first 2 years at the medical school were uneventful and I was thinking of dropping out. Things changed at the 3rd year, when I first studied anemias in detail and indulged in the beauty of their differential diagnosis. I was struck by their mesmerizing complexity and kept reading multiple times the anemias section in Cecil Textbook of Medicine. My final decision to become a hematologist was made when I met my mentor, Professor Costas Tsatalas. His vitality and passion when he was analyzing intriguing hematological cases, made all other specialties look so mundane to my enthusiastic student's eyes. I never regretted my choice, hematology keeps surprising me every day making feel like a first-year resident.

DO YOU HAVE ANY ADVICE FOR OUR READERS?

For my fellow colleagues, I strongly recommend to visit regularly the MDSF site and enjoy its pluralistic sources and types of up-to-date medical information. The same recommendation applies for patients MDS patients and their relatives, but I advise them to avoid digging into complex scientific issues – they will only be even more confused and frustrated. MDSF has an amazing, reader-friendly patient section that answers almost every concern an MDS patient want to know.

WELCOME TO THE **PROFESSIONAL SECTION** OF THE MDS FOUNDATION NEWSLETTER

Meeting Highlights and Announcements

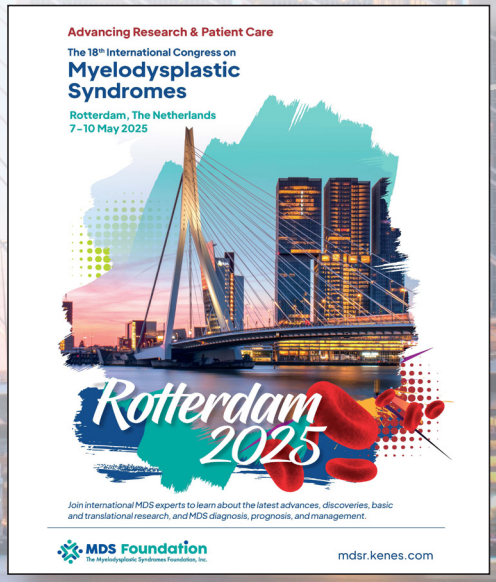
ADVANCING RESEARCH & PATIENT CARE

The 18th International Congress on Myelodysplastic Syndromes

ROTTERDAM, THE NETHERLANDS • 7-10 MAY 2025

https://mds.kenes.com

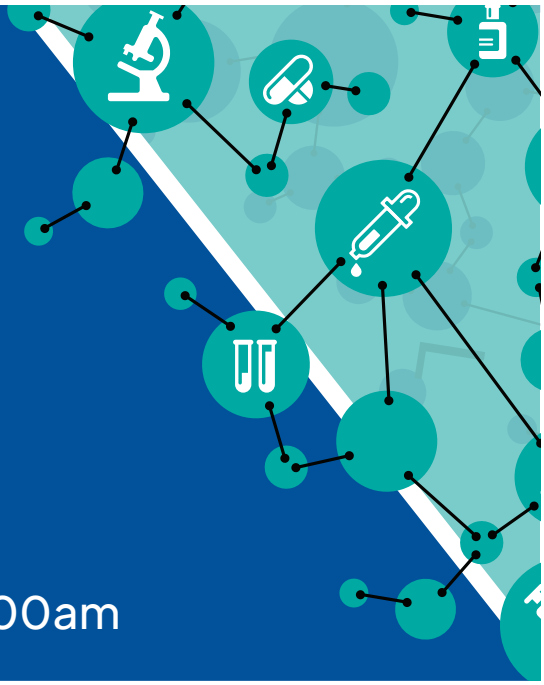
STAY TUNED FOR MORE DETAILS



Rotterdam 2025

MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.

This is a Friday Satellite Symposium preceding
The 66th American Society of Hematolog
Annual Meeting



Breakfast Symposium

MDS 2024: Let's Overcome the Challenges

Friday, December 6, 2024 • 7:00–10:00am

TENTATIVE SCIENTIFIC PROGRAM

Challenges in MDS – 2024	Moshe Mittelman
Lecture I: Minimal Residual Disease	Magnus Tobiasson
Debate I: The approach for RBC transfusion policy	Liberal: Rena Buckstein Restrictive: Esther Oliva
Patient Discussion	
Debate II: A role for anti-inflammatory treatment	Yes: Lachelle Weeks No: Lionel Ades
Lecture II: Who should be screened for germline mutations?	Jaroslaw Maciejewski
Debate III: Treatment of HR-MDS (in 2024)	HMA only: Ghulam Mufti HMA in combination: Aristoteles Giagounidis

STAY TUNED FOR MORE INFORMATION

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The Myelodysplastic Syndromes Foundation, Inc.

AKH INC.
ADVANCING KNOWLEDGE IN HEALTHCARE

This activity is jointly-provided by The Myelodysplastic Syndromes Foundation, Inc. and AKH Inc., Advancing Knowledge in Healthcare.

15–16 MARCH 2024, KYOTO JAPAN

The Third Regional Symposium on Myelodysplastic Syndromes (MDSR2024)

The Third Regional Symposium on Myelodysplastic Syndromes (MDSR2024) was held on 15–16 March, 2024 at the Kyoto International Conference Center in Kyoto, Japan. The chairpersons, Seishi Ogawa, Professor of Department of Tumor Biology, Kyoto University, and Yasushi Miyazaki at Atomic Bomb Disease Research Institute, Nagasaki University welcomed all participants.

Preparations for this symposium started in 2021 with the aim of having the regional symposium in Japan in 2022. However, due to the COVID-19 pandemic, the local organizing committee and the members of the Medical and Scientific Advisory Board (MSAB) members of the MDS Foundation found it very difficult to hold this symposium in person in 2022. Because direct discussion between researchers or between presenters and participants is the key issue of the Regional Symposium, we decided to postpone it to 2024, and it became real this time. We are very happy to make it possible, finally. In the MDSR2024, there were 198 participants from 19 countries, including Asian and Oceanian countries. It is also important to have participants from the areas around Japan.

Each year, the Regional Symposium (2-day program) and the International Symposium on MDS (4-day program) alternate and complement each other.
Both meetings are basically a plenary format, with lectures held at one venue. Regional Symposia are held in areas beyond the reach of the International Symposia and are more focused on local MDS researchers and physicians. The MDSR2024 had a two-day program, following the previous Regional Symposium.

The MDSR2024 began with a welcome from Dr. Nimer, Chairman of the Board of Directors of the MDS Foundation. He introduced various activities of the MDS Foundation, and emphasized the importance of promoting basic and clinical research for MDS patients. Professor Ogawa then gave an opening speech in which he hoped for a lively discussion, and the symposium lectures began.

In the first session, there were three presentations on the classification and prognosis of MDS. Drs. Bernard and Maciejewski presented new aspects of the molecular classification of MDS, and prognostication of MDS, followed by Dr. Daver. He spoke about the treatment of *TP53*-mutated MDS, which shows a poor response to treatment and is one of the major challenges in the treatment of MDS. Dr. Bejar, then, gave a talk about the two classifications for MDS that were published in 2022: the 5th edition of the WHO classification and the International Consensus Classification (ICC), pointing out the similarities and differences between them.

It was a very valuable opportunity to hear directly from world-leading researchers in their respective fields, such as Dr. Beck's lecture on VEXAS syndrome, and Dr. Ebert's presentation on clonal hematopoiesis.

On the second day, Dr. Bennett, an original member of French-American-British classification of MDS, gave a lecture on MDS morphology. He emphasized the importance of morphologic assessment for the accurate diagnosis of MDS. After his lecture, we had two presentations on the future of MDS diagnosis by

Preparations for this symposium started in 2021 with the aim of having the regional symposium in Japan in 2022. However, due to the COVID-19 pandemic, the local organizing committee and the members of the Medical and Scientific Advisory Board (MSAB) members of the MDS Foundation found it very difficult to hold this symposium in person in 2022. Because direct discussion between researchers or between presenters and participants is the key issue of the Regional Symposium, we decided to postpone it to 2024, and it became real this time. We are very happy to make it possible, finally. In the MDSR2024, there were 198 participants from 19 countries, including Asian and Oceanian countries. It is also important to have participants from the areas around Japan.

Dr. Bruck from Finland, and Dr. Haferlach from Germany. In their talk, they discussed the state of the art for morphological diagnosis using AI, and comprehensive diagnosis of MDS, such as morphology, flow cytometry, cytogenetics, and genome analysis with deep support from AI. I am sure that his presentation gave the participants strong confidence that the use of AI will further advance in the diagnosis of MDS will be further advanced very soon.

A case study was also conducted at this meeting, with Drs. Bejar, Zeidan, and Miyazaki as a panel to discuss higher- and lower-risk MDS cases, moderated by Dr. Mittelman. Discussions based on actual cases led to a lively exchange of opinions with the participants, which clearly, and repeatedly demonstrated how wide the range of clinical manifestations of MDS.

In addition to above, there were sessions on MDS treatment response criteria, treatment for lower-risk and higher-risk MDS, new drug development, and chronic myelomonocytic leukemia, allowing participants to listen to the latest information on various aspects of MDS over the course of two days.

In each session, there were many questions and discussions after each presentation, so that we had to shorten the break and lunch times. However, we believe that this kind of interaction between researchers is extremely important, and we would like to reiterate the importance of this meeting. We believe that there was great significance in holding the event locally.

I also believe that the MDSR2024 gave participants the opportunity for participants to experience various aspects of Japanese culture in Kyoto. Kiyomizu Temple is one of the most representative temples in Kyoto (World Heritage). The calligraphy written as "Meikyo Shisui'" is famous there, which means a mirror with no clouding, and the clear surface of water without a single ripple, showing calm mind without any evil thought. This word is widely known in Japan, and is considered an important attitude when approaching things. I hope that the participants attended the MDSR2024 with this attitude.

This symposium would not be possible without kind and warm support of MSAB members, and staffs of MDS Foundation, especially Dr. Mittelman, and Ms. Harrison. We deeply appreciate their kind help for MDSR2024. We hope that it was a good opportunity for everyone who participated in this symposium to deepen their knowledge of about MDS, exchange new and old friendship, and experience Japanese culture.

The 18th International MDS Symposium will be held in Rotterdam, The Netherlands, from May 7th to 10th, 2025. We look forward to seeing you all in Rotterdam next year.

PATIENT SUMMARY

ASH 2023 FRIDAY SATELLITE SYMPOSIUM
DECEMBER 8, 2023

Myelodysplastic Syndromes 2023: What's New?

The Symposium brought together an international faculty of experts who presented, debated, and discussed recent advances in myelodysplastic syndromes (MDS). This summary describes the presentations, highlighting current challenges, new developments, as well as potential future approaches to improve the diagnosis and treatment of MDS.

SUMMARIES OF THE PRESENTATIONS

MDS CHALLENGES IN 2023

Moshe Mitelman from the Tel-Aviv Sourasky Medical Center, Tel-Aviv University, Israel, outlined some of the current challenges and unmet medical needs in MDS. The diagnosis of MDS still relies on bone marrow tests and a need exists for new diagnostic tools which are less invasive and more accurate. It is also important to try and diagnose patients earlier and identify those patients with pre-MDS states who are at risk for progression. Currently there are several different systems that can be used to classify MDS. This can complicate diagnosis and management decisions and so it may be beneficial if the current classification systems were combined into one system.

Many challenges remain in the treatment of MDS. For lower-risk (LR)-MDS, red blood cell transfusions and erythropoietin stimulating agents (ESAs) have been used to treat anemia for many decades; more effective and newer agents are needed. Similarly for thrombocytopenia, safe and effective treatments are needed. For higher-risk (HR)-MDS, hypomethylating agents (HMAs) remain the standard initial treatment. However, as only half of patients respond to treatment, with most patients losing response within 2 years, newer treatment strategies need to be investigated to improve outcomes for patients.

A CLASSIFICATION OF MYELODYSPLASTIC SYNDROMES THAT AIDS CLINICAL DECISION MAKING

Next-generation sequencing (NGS) is a powerful technology that can capture a large amount of genomic information about a cancer. Mario Cazzola from the Fondazione IRCCS Policlinico San Mateo and University of Pavia, Italy discussed the implications of NGS on the diagnosis, classification, and prognosis of MDS. Focusing on a type of MDS called MDS with ring sideroblasts, NGS has revealed different subgroups within this type of MDS, depending on which gene is mutated. This is relevant because some gene mutations (e.g. *SRSF2* and *TP53*) are associated with poor prognosis, whereas others (e.g. *SF3B1*) are associated with a beter prognosis. Therefore, developing a classification of MDS based on the different genomic subtypes may significantly help clinical decision-making.

PRE-MDS STATES – HOW TO MANAGE IN THE CLINIC?

Michael R. Savona from the Vanderbilt University School of Medicine, Nashville, Tennessee, USA delivered a detailed presentation about clonal hematopoiesis (CH), which is a common aging-associated condition that may evolve over time to MDS and other blood cancers. He also described the CHIVE (**C**lonal **H**ematopoiesis and **I**nflammation in the **V**asculatur**E**) project which is a registry and repository aimed at understanding the natural history of CH. Patients with CH, or those at risk for CH, provide blood and tissue samples at scheduled visits and are monitored over time for any changes. As well as increasing understanding of CH, it is hoped that this project will help to shape care for patients with CH and ultimately lead to guidance for clinical trials.

DEBATE I: ESA- STILL THE 1ST LINE FOR LR-MDS?

No perspective

Mateo G Della Porta, from the Humanitas Research Hospital, Milan, Italy began by highlighting that anemia not only negatively affects quality of life, but also reduces the life expectancy of patients with LR-MDS. Therefore, one of the main goals of treatment is to manage anemia and its associated complications. Two-thirds of patients either don't experience a response to ESAs or relapse, so there is an urgent need for a more effective treatment option. One such option is luspatercept which was approved in 2020 by the US Food and Drug Administration (FDA) for the treatment of anemia in patients with low- to intermediate-risk MDS who had failed to respond to an ESA. Luspatercept is an erythroid maturation agent and works differently than ESAs. Interim results from an ongoing clinical trial called COMMANDS showed that luspatercept was beter than ESAs when used as first-line treatment for patients with transfusion-dependent LR-MDS. Treatment with luspatercept resulted in significant improvements in red blood cell transfusion independence and hemoglobin increase (the trial primary endpoint), and improvements in the duration of response compared with ESA.

Yes perspective

Aristoteles Giagounidis from the Marien Hospital, Düsseldorf, Germany delivered a lively rebutal, also presenting the result of the COMMANDS trial, but focusing on the characteristics of the patients who were included in the trial. The inclusion criteria of the COMMANDS trial stipulated that patients had to be transfusion dependent and have an endogenous erythropoietin (EPO) level of <500 U/L. However, most patients with LR-MDS will be diagnosed before they become transfusion dependent. In addition, it is known that ESAs work best in patients with non-transfusion dependent anemia and an EPO level of <200 U/L. When looking at subgroups in the COMMANDS trial, ESAs were more effective at achieving the primary endpoint in one subgroup of patients: those who had ring sideroblast–negative status. Therefore, ESA should remain as standard-of-care for LR-MDS in patients who are not transfusion dependent, have an EPO level of <200 U/L and ring sideroblast–negative.

ARTIFICIAL INTELLIGENCE IN MDS PRACTICE

Aziz Nazha, from the Thomas Jefferson University, Philadelphia, PA, USA and the AI Innovations Institute, Incyte gave an overview of the current applications of Artificial Intelligence (AI) in the diagnosis and management of MDS. AI-powered models can improve the accuracy and efficiency of diagnosing MDS, are able to predict disease progression and transformation to acute myeloid leukemia (AML), and also optimize treatment selection. Looking to the future, generative AI (e.g. ChatGPT) has the potential to revolutionize MDS and cancer research.

CAN WE DO BETTER THAN HMA ALONE IN HR-MDS?

Treatment options for patients with HR-MDS include HMAs, AML-like therapies and stem cell transplantation (SCT). Guillermo Garcia-Manero from the University of Texas MD Anderson Cancer Center, Houston, TX, USA explained that no other treatment has been shown to be superior to single agent azacitidine in a randomized clinical trial and SCT is still restricted to fit patients with a suitable donor

New classifications and molecular data are helping to understand different subsets of patients. As a consequence, the definition of HR-MDS is evolving. For example, a patient who would have previously been classified as lower risk, may now be classified as high-risk based on molecular testing results. The implications on how this affects treatment decisions remains unclear.

HMAs, including decitabine or azacitidine, are recommended as standard-of-care treatment for patients with HR-MDS. Until a few years ago, the only option was to give HMAs by intravenous (IV) or subcutaneous (SC) infusion which caused a significant burden on patients. In 2020, an oral form of

HMA - a combination of decitabine and cedazuridine – was approved by the FDA for the treatment of MDS, therefore reducing the need for patients to visit the clinic so frequently. HMAs in combination with another treatment (also referred to as 'doublets') are currently being investigated in clinical trials. Notably, the Phase 3

VERONA trial is investigating the combination of azacitidine and venetoclax and the results are eagerly anticipated in 2024.

DEBATE II: SHOULD CYTOREDUCTION PRECEDE TRANSPLANT?

Yes…if…

Uwe Platzbecker from the University Hospital Leipzig, Leipzig, Germany highlighted that the value of treating patients with HMA or chemotherapy before allogeneic transplantation is not clear and has not been studied in randomized clinical trials. Retrospective analyses have shown that treatment with a HMA before transplant improves outcomes in patients who are in complete remission compared with patients who have active disease at the time of transplant. However, HMA and induction chemotherapy can also cause short-term toxicity and many patients with MDS tend to have a delayed recovery of their blood counts. This leaves the question of when and how to 'bridge' to transplant. New combination therapies, such as azacitidine and venetoclax, may pave the way for new, effective treatments before transplant.

Not routinely

Christopher Gibson from the Dana Farber Cancer Institute, Boston, MA, USA argued that routine cytoreduction before transplant is not supported by current evidence and can sometimes be counterproductive. There are no data to show that cytoreduction before transplant improves patient outcomes. In addition, there is a risk that patients become ineligible for transplant while they are receiving cytoreductive treatment due to disease progression to AML or adverse effects such as infections.

Dr Gibson concluded his presentation by summarizing what he does in clinical practice:

- **Does not cytoreduce** in patients with <5% blasts or in patients who are borderline transplant candidates.
- **Nearly always cytoreduces** patients with rapidly increasing blast counts, or patients with 10–20% blast counts.
- **Sometimes cytoreduces** patients with 5–10% blast counts depending on the disease trajectory and clinical scenario.

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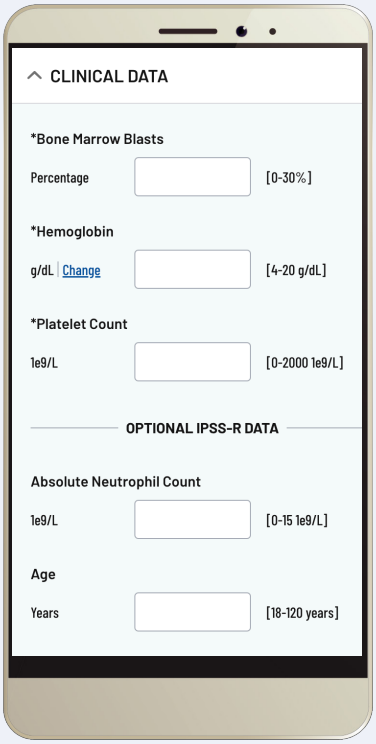
MDS Risk Assessment Calculators

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).



IPSS-M CALCULATOR

The IPSS-M is the newest MDS prognosis calculator that combines genomic profiling with hematologic and cytogenetic parameters, improving the risk stratification of patients with MDS.

This is a valuable tool for clinical decision-making, offering the prospect of tailoring diagnosis and therapeutic interventions to each patient's molecular profile.

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

DOWNLOAD IPSS-M CALCULATOR APP

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

DOWNLOAD IPSS-R CALCULATOR APP

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

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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 ~July 19, 2024.

Q4:2023

Centers of Excellence Referrals

Cedars-Sinai (1); Indiana University; Loyola (1); MD Anderson (1); Mount Sinai (1); Northwestern (1); Stanford (1); UCLA (1); UNC Lineberger (1); UT Southwestern (1); Washington University School of Medicine (1)

Total Referrals: 11 (12.7% 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	45 (52.3%)
Looking for educational resources	19 (22.09%)
Discussed clinical trials and SparkCures	16 (18.6%)
Seeking information on webinars/forums/events	4 (4.6%)
Questions requiring provider input	8 (9.3%)
Needing financial resources	10 (11.6%)
Fundraising and donations	5 (5.8%)

Q1:2024

Centers of Excellence Referrals

Barbara Ann Karmonas Cancer Institute (1); Columbia (1); Dana-Farber (1); Indiana University (1); Johns Hopkins (1); Loyola University Medical Center (1); Mayo Clinic Rochester (1); Mental Health Referrals (2) (facilitated by Mass General & William Beaumont Hospital Cancer Center); Moffit (3); Rush University Medical Center (1); Vanderbilt (1); Washington University School of Medicine (1)

Total Referrals: 15 (14.9% 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	27 (20.45%)
Looking for educational resources	26 (19.70%)
Discussed clinical trials and SparkCures	13 (9.85%)
Seeking information on webinars/forums/events	12 (9.09%)
Questions requiring provider input	5 (3.79%)
Needing financial resources	7 (5.30%)
Fundraising and donations	7 (5.30%)

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

METRICS

13-WEEK SUMMARY
10/22/23 – 01/19/24

No. of unique patients/ caregivers who called in: **38**

No. of unique patients/ caregivers who emailed: **30**

Message boards answered: **17**

Move for MDS Follow-Ups: **1**

AS OF 01/19/24:

Assisted **86** different patients/caregivers/friends in 13 weeks (~6.6 patients per week)

13-WEEK SUMMARY
01/20/24 – 04/19/24

No. of unique patients/ caregivers who called in: **55**

No. of unique patients/ caregivers who emailed: **39**

Message boards answered: **7**

AS OF 04/19/24:

Assisted **101** different patients/caregivers/friends in 13 weeks (~7.7 patients per week)

SUPPORT GROUPS

have been requested in the following locations:*

CALIFORNIA • NEW JERSEY • PHILIPPINES

**Plus more virtual groups*

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SPECIAL ANNOUNCEMENT
NEW APPROVAL

Geron Announces FDA Approval of RYTELO™ (imetelstat), a First-in-Class Telomerase Inhibitor, for the Treatment of Adult Patients with Lower-Risk MDS with Transfusion-Dependent Anemia

Approval across ESA ineligible and ESA relapsed/refractory patients with LR-MDS with transfusion-dependent anemia, regardless of ring sideroblast (RS) status

Durable and sustained red blood cell transfusion independence, increases in hemoglobin levels and reduction in transfusion burden observed across key LR-MDS subgroups in the IMerge Phase 3 clinical trial; the most common Grade 3/4 adverse reactions were thrombocytopenia and neutropenia, which were generally manageable and short-lived

Lower-risk MDS is a progressive blood cancer with high unmet need, where many patients with anemia become dependent on red blood cell transfusions, which can be associated with clinical consequences and decreased quality of life

FOSTERCITY, CA — JUNE 6, 2024 (BUSINESS WIRE). Geron Corporation (Nasdaq: GERN), a commercial-stage biopharmaceutical company aiming to change lives by changing the course of blood cancer, today announced that the U.S. Food and Drug Administration (FDA) has approved RYTELO™ (imetelstat) for the treatment of adult patients with low- to intermediate-1 risk myelodysplastic syndromes (MDS) with transfusion-dependent (TD) anemia requiring four or more red blood cell units over eight weeks who have not responded to or have lost response to or are ineligible for erythropoiesis-stimulating agents (ESA).

"With the approval and availability of RYTELO, we believe eligible patients with lower-risk MDS can potentially experience meaningful clinical benefit, particularly the potential for greater than 24 weeks of freedom from the burden of red blood cell transfusions and symptomatic anemia," said John A. Scarlett, M.D., Geron's Chairman and Chief Executive Officer. "The approval of RYTELO as the first telomerase inhibitor is a testament to the power of our science and the passion of our people to innovate in the field of blood cancer. As we celebrate today's momentous milestone, I would like to thank the patients and families, advocates, clinicians, study coordinators and site personnel, scientists, and Geron employees and collaborators past and present whose participation was integral to this achievement and to supporting our transformation into a commercial company."

Lower-risk myelodysplastic syndromes (LR-MDS) is a blood cancer that often progresses to require increasingly intensified management of key symptoms such as anemia and resulting fatigue.[1] These symptomatic LR-MDS patients frequently become red blood cell transfusion dependent, which has been shown to be associated with short- and long-term clinical consequences that reduce quality of life and shorten survival.[2,3] There is a high unmet need for many LR-MDS patients, particularly those with characteristics having poorer prognosis. Current treatment options for those failing ESA are limited to select sub-populations and there is an unmet need for treatments that can provide extended and continuous red blood cell transfusion independence.

APPROVAL BASED ON RESULTS FROM IMERGE PHASE 3 CLINICAL TRIAL

"For patients with lower-risk MDS and anemia who are transfusion dependent, we have very few options today and often cycle through available therapies, making the approval of RYTELO potentially practice changing for us," said Rami Komrokji, MD, Vice Chair, Malignant Hematology Department, Moffitt Cancer Center, who was an investigator of the pivotal IMerge clinical trial. "What is exciting about RYTELO is the totality of the clinical benefit across LR-MDS patients irrespective of ring sideroblast status or high transfusion burden, including sustained and durable transfusion independence and increases in hemoglobin levels, all within a well-characterized safety profile of generally manageable cytopenias. The treatment goal for patients with LR-MDS and anemia is transfusion independence and before today, this wasn't possible for many patients."

What is exciting about RYTELO is the totality of the clinical beneít across LR-MDS patients irrespective of ring sideroblast status or high transfusion burden, including sustained and durable transfusion independence and increases in hemoglobin levels, all within a well-characterized safety proíle of generally manageable cytopenias. The treatment goal for patients with LR-MDS and anemia is transfusionindependence and before today, this wasn't possible for many patients."

Rami Komrokji, MD, Vice Chair,
Malignant Hematology Department
Mott Cancer Center

The FDA approval of RYTELO is based on results from the IMerge Phase 3 clinical trial, published in *The Lancet*.[4] The IMerge trial met its primary and key secondary endpoints, with RYTELO demonstrating significantly higher rates of red blood cell transfusion independence (RBC-TI) versus placebo for at least eight consecutive weeks (RYTELO 39.8% [95% CI 30.9–49.3]; placebo 15.0% [7.1–26.6]; p<0.001) and for at least 24 weeks (RYTELO 28.0% [95% CI 20.1–37.0]; placebo 3.3% [95% CI 0.4–11.5]; p<0.001). RBC-TI was durable and sustained in the RYTELO treated population, with a median RBC-TI duration for 8–week responders and 24–week responders of approximately 1 year and 1.5 years, respectively.

In an exploratory analysis of RYTELO-treated patients achieving ≥8–week RBC-TI, median increases in hemoglobin were 3.6 g/dL for RYTELO and 0.8 g/dL for placebo. Clinically meaningful efficacy results were observed across key MDS subgroups irrespective of ring sideroblast (RS) status, baseline transfusion burden and IPSS risk category.

In the IMerge trial, the safety profile of RYTELO was well-characterized with generally manageable and short-lived thrombocytopenia and neutropenia, which are familiar side effects for hematologists who are experienced with managing cytopenias. The most common Grade 3/4 adverse reactions were neutropenia (72%) and thrombocytopenia (65%), which lasted a median duration of less than two weeks, and in more than 80% of patients were resolved to Grade < 2 in under four weeks. Cytopenias were generally manageable with dose modifications.

The intravenous administration of RYTELO every four weeks aligns to routine blood count monitoring for these patients.

The most common adverse reactions (incidence≥ 10% with a difference between arms of >5% compared to placebo), including laboratory abnormalities, were decreased platelets (thrombocytopenia), decreased white blood cells, decreased neutrophils (neutropenia), increased aspartate aminotransferase (AST), increased alkaline phosphatase (ALP), increased alanine aminotransferase (ALT), fatigue, prolonged partial thromboplastin time, arthralgia/myalgia, COVID-19 infections, and headache. Clinically relevant adverse reactions in <5% of patients who received RYTELO included febrile neutropenia, sepsis, gastrointestinal hemorrhage, and hypertension.

ABOUT RYTELO™ (IMETELSTAT)

RYTELO™ (imetelstat) is an FDA-approved oligonucleotide telomerase inhibitor for the treatment of adult patients with low-to-intermediate-1 risk myelodysplastic syndromes (LR-MDS) with transfusion-dependent anemia requiring four or more red blood cell units over eight weeks who have not responded to or have lost response to or are ineligible for erythropoiesis-stimulating agents (ESAs). It is indicated to be administered as an intravenous infusion over two hours every four weeks.

RYTELO is a first-in-class treatment that works by inhibiting telomerase enzymatic activity. Telomeres are protective caps at the end of chromosomes that naturally shorten each time a cell divides. In LR-MDS, abnormal bone marrow cells often express the enzyme telomerase, which rebuilds those telomeres, allowing for uncontrolled cell division. Developed and exclusively owned by Geron, RYTELO is the first and only telomerase inhibitor approved by the U.S. Food and Drug Administration.

Geron aims to ensure broad access to RYTELO for eligible patients. Accordingly, our REACH4RYTELO™ Patient Support Program provides a range of resources that support access and affordability to eligible patients prescribed RYTELO.

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Syros Reports First Quarter 2024 Financial Results and Provides a Corporate Update

Passed Interim Futility Analysis of the Primary Endpoint in Phase 3 SELECT-MDS-1 Trial of Tamibarotene; Pivotal CR Data Expected by Mid-4Q 2024; Company to Host HR-MDS-focused Webcast Event with Medical Experts on June 25, 2024

Received FDA Fast Track Designation for Tamibarotene for the Treatment of Unfit AML; Additional Data from SELECT-AML-1 Phase 2 Trial Expected in 3Q24

CAMBRIDGE, MA — MAY 14, 2024 (BUSINESS WIRE). Syros Pharmaceuticals (NASDAQ: SYRS), a biopharmaceutical company committed to advancing new standards of care for the frontline treatment of hematologic malignancies, today reported financial results for the quarter ended March 31, 2024 and provided a corporate update.

"In 2024, we are acutely focused on execution across clinical and pre-commercial activities as we advance tamibarotene toward critical milestones, including additional data from the Phase 2 SELECT-AML-1 trial in the third quarter and pivotal CR data from the Phase 3 SELECT-MDS-1 trial in the fourth quarter," said Conley Chee, Chief Executive Officer of Syros. "We are particularly pleased to share today that an independent data monitoring committee recently completed a pre-specified interim futility analysis on 50% of the patients enrolled in the SELECT-MDS-1 trial to support our primary endpoint analysis, and recommended that our study continue without modification. This recommendation, together with the FDA's decision to grant Fast Track Designation to tamibarotene in AML, reinforces our confidence in the potential for our RARα agonist to offer improved clinical outcomes to HR-MDS and AML patients with *RARA* gene overexpression, supported by our belief that tamibarotene has a differentiated safety profile well suited for use in these patients."

Mr. Chee continued, "In addition, following the completion of enrollment in the first quarter of 2024 of the 190 patients necessary for our primary endpoint analysis in the Phase 3 SELECT-MDS-1 trial, we have begun preparing for our first New Drug Application filing and subsequent launch in the United States. We look forward to engaging further with the medical community to drive awareness of tamibarotene and the companion diagnostic to identify *RARA* overexpression in patients with higher-risk MDS, as we work to deliver tamibarotene as the new frontline standard-of-care for patients with RARA overexpression."

Syros today announced plans to host a webcast event on June 25, 2024 to discuss disease biology and the current treatment landscape in HR-MDS, as well as the design of the ongoing pivotal Phase 3 SELECT-MDS-1 trial and opportunity for tamibarotene. The event will feature presentations from medical experts, in addition to Syros management. The event will be webcast live on the Investors & Media section of Syros' website, www.syros.com. More details for the event are forthcoming.

UPCOMING MILESTONES

- Report pivotal complete response (CR) data from the SELECT-MDS-1 Phase 3 trial in newly diagnosed HR-MDS patients with *RARA* gene overexpression by the middle of the fourth quarter of 2024.
- Report clinical activity and tolerability data from a prespecified analysis of over 40 patients from the SELECT-AML-1 Phase 2 trial in unfit AML patients with *RARA* overexpression in the third quarter of 2024.

RECENT PIPELINE HIGHLIGHTS

In March, the Phase 3 SELECT-MDS-1 clinical trial of tamibarotene passed a pre-specified interim futility analysis based on the CR rate, which was conducted by an Independent Data Monitoring Committee (IDMC). There were no concerning safety signals noted in the analysis and the IDMC recommended SELECT-MDS-1 continue without modification. Syros remains blinded to the data.

In April, the U.S. Food and Drug Administration (FDA) granted Fast Track Designation to tamibarotene in combination with venetoclax and azacitidine for the treatment of newly diagnosed AML with *RARA* overexpression, as detected by an FDA approved test in adults who are over age 75 and who have comorbidities that preclude the use of intensive induction chemotherapy. The FDA previously granted this designation to tamibarotene in combination with azacitidine for the treatment of adults with HR-MDS and *RARA* overexpression in January 2023.

First Quarter 2024 Financial Results

- The Company did not recognize any revenue in the first quarter of 2024, as compared to $3.0 million for the first quarter of 2023. The decrease reflects the termination of Syros' collaboration agreement with Pfizer.
- Research and development (R&D) expenses were $24.7 million for the first quarter of 2024, as compared to $28.8 million for the first quarter of 2023. The decrease was primarily due to the reduction in external R&D consulting, contract manufacturing, and a reduction in headcount and related expenses.
- General and administrative (G&A) expenses were $6.3 million for the first quarter of 2024, as compared to $7.4 million for the first quarter of 2023. The decrease was primarily due to a reduction of headcount and related expenses, consulting fees, and facilities expenses.
- For the first quarter of 2024, Syros reported a net loss of $3.7 million, or $0.10 per share, compared to a net loss of $23.8 million, or $0.85 per share, for the same period in 2023.

Rigel Announces Publication of Data on REZLIDHIA® (Olutasidenib) in Post-Venetoclax Patients with Mutant IDH1 AML in Leukemia & Lymphoma

Olutasidenib induced durable composite complete remission in 43.8% of patients relapsed or refractory to prior venetoclax-based regimens

Safety was consistent with the overall profile of olutasidenib

Olutasidenib may offer a valuable treatment option for patients with m*IDH1* previously treated with venetoclax

SOUTH SAN FRANCISCO, CA — APRIL 4, 2024 (PRNEWSWIRE). Rigel Pharmaceuticals, Inc. (Nasdaq: RIGL) today announced a peer-reviewed publication in *Leukemia & Lymphoma* on data from an analysis of the Phase 2 study evaluating REZLIDHIA® (olutasidenib), a potent, selective, oral, small-molecule inhibitor of mutant isocitrate dehydrogenase-1 (m*IDH1*)[1], in patients with m*IDH1* acute myeloid leukemia (AML) who were relapsed/refractory (R/R) to prior venetoclax-based regimens.

"Venetoclax in combination with a hypomethylating agent is currently standard treatment for patients with newly diagnosed AML who are unfit for intensive chemotherapy, including those with mIDH1. When this therapy fails, patients historically have had limited treatment options and poor prognoses," said Jorge E. Cortes, M.D., Director, Georgia Cancer Center, Cecil F. Whitaker Jr., GRA Eminent Scholar Chair in Cancer, and Phase 2 trial investigator. "The findings from these analyses suggest that REZLIDHIA may provide an effective treatment for patients with AML following failure of venetoclax combination therapy. REZLIDHIA induced durable remissions consistent with those observed in the pivotal trial and had a favorable tolerability profile in this challenging to treat patient population, representing a valuable treatment option."

"These data support REZLIDHIA's efficacy and well-characterized safety profile in patients with m*IDH1* R/R AML who had previously been treated with venetoclax combination regimens," said Raul Rodriguez, Rigel's president and CEO. "These analyses are important because they provide valuable insights into the potential benefit of REZLIDHIA in different segments of the m*IDH1* R/R AML patient population."

Key points from the paper are summarized below:

- Olutasidenib alone or in combination with azacitidine demonstrated potential efficacy in patients with AML following failure of venetoclax combination therapy
- Of the 18 patients with prior venetoclax treatment, 10 were relapsed, 6 were refractory, and 2 had complete remission with incomplete hematologic recovery (CRi) to a venetoclax combination
- Of the 16 R/R patients, 7 (43.8%) achieved a composite complete remission (CRc), 4 (25%) achieved complete remission (CR), and 1 (6.3%) achieved CR with partial hematologic recovery (CRh). Both patients with CRi at study entry achieved CR
- Median time to CRc was 1.9 months (range 1–2.8). As of the data cut-off (June 18, 2021), median duration of CRc was not reached (range, 1.2–NR, ongoing at 30.4+ months)
- Red blood cell and platelet transfusion independence was achieved in 2/12 (17%) and 2/7 (29%) transfusion-dependent R/R patients at baseline, respectively
- Safety was consistent with the overall profile of olutasidenib

The paper, titled "Olutasidenib in post-venetoclax patients with mutant isocitrate dehydrogenase 1 (mIDH1) acute myeloid leukemia (AML)," was published online in *Leukemia & Lymphoma*.

ABOUT AML

Acute myeloid leukemia (AML) is a rapidly progressing cancer of the blood and bone marrow that affects myeloid cells, which normally develop into various types of mature blood cells. AML occurs primarily in adults and accounts for about 1 percent of all adult cancers. The American Cancer Society estimates that there will be about 20,800 new cases in the United States, most in adults, in 2024.[2]

Relapsed AML affects about half of all patients who, following treatment and remission, experience a return of leukemia cells in the bone marrow.[3] Refractory AML, which affects between 10 and 40 percent of newly diagnosed patients, occurs when a patient fails to achieve remission even after intensive treatment.[4] Quality of life declines for patients with each successive line of treatment for AML, and well-tolerated treatments in relapsed or refractory disease remain an unmet need.

ABOUT REZLIDHIA®

INDICATION:

REZLIDHIA is indicated for the treatment of adult patients with relapsed or refractory acute myeloid leukemia (AML) with a susceptible isocitrate dehydrogenase-1 (IDH1) mutation as detected by an FDA-approved test.

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Press Releases

Taiho Oncology Announces Publication of Final Results of the Phase 3 Ascertain Clinical Trial of Oral Decitabine and Cedazuridine Fixed Dose Combination (Inqovi®) in Patients With MDS and CMML

PRINCETON, NJ — JANUARY 23, 2024. Taiho Oncology, Inc. announces publication of the final results from the pivotal ASCERTAIN clinical trial of fixed-dose oral decitabine and cedazuridine (INQOVI®) compared to intravenous decitabine in adults with intermediate and high-risk myelodysplastic syndromes (MDS) including chronic myelomonocytic leukemia (CMML).[1]

The ASCERTAIN trial was the first Phase 3 trial to demonstrate pharmacologic equivalence between an oral and an intravenous (IV) formulation of a hypomethylating agent for use in the treatment of patients with MDS or CMML. As reported in the January 2 issue of *The Lancet Haematology*, median overall survival (mOS) in the trial population was approximately 32 months.[1] In addition, the overall response rate was 62% in the intent to treat patient population. The percentage of patients in this trial who moved to transplantation reached 20%, exceeding expected transplantation rates in patients receiving hypomethylating agents for MDS and CMML.[1]

Safety findings from the study were comparable with those previously observed with IV decitabine. The most common treatment-emergent adverse events of thrombocytopenia, neutropenia and anemia were consistent with expected adverse events with parenteral hypomethylating agent treatment.

The data from the study supported the simultaneous approval of INQOVI® by the U.S. Food and Drug Administration and Health Canada in July 2020 for the treatment of adult patients with myelodysplastic syndromes (MDS), including previously treated and untreated, de novo and secondary MDS with the following French-American-British subtypes (refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, and chronic myelomonocytic leukemia [CMML]) and intermediate-1, intermediate-2, and high-risk International Prognostic Scoring System groups.[2]

"Until recently, azacitidine and decitabine, both widely used hypomethylating agents, were available only in parenteral form, requiring patients with MDS and CMML to travel to treatment centers daily for 5 or 7 consecutive days of each 28-day treatment cycle," said Guillermo Garcia-Manero, MD, Professor, Department of Leukemia, Division of Cancer Medicine, the University of Texas MD Anderson Cancer Center, Houston, and the lead author on the publication. "The ASCERTAIN study has demonstrated that the orally delivered fixed dose combination of decitabine and cedazuridine is an alternative option to parenteral administration of decitabine for patients with these diseases. The observed median overall survival of greater than 30 months in the ASCERTAIN study compared with historical controls is encouraging."

Added Tehseen Salimi, MD, MHA, Senior Vice President and Head of Medical Affairs, Taiho Oncology, Inc., "Patients living with MDS and CMML can benefit from the convenience of an at-home hypomethylating agent treatment that may potentially reduce the number of office visits and the travel that comes with it."

ABOUT THE ASCERTAIN TRIAL

The Phase 3 ASCERTAIN clinical trial was a multicenter, randomized, open-label, crossover pharmacokinetics (PK) study comparing oral decitabine (35mg) and cedazuridine (100mg) fixed-dose combination tablet given once daily for 5 days on a 28-day cycle to IV decitabine (20mg/m^2) administered as a daily 1-hour IV infusion for 5 days on a 28-day cycle, in the first 2 cycles in patients with MDS and CMML. Patients continued to receive oral decitabine and cedazuridine from Cycle 3 onwards. The primary endpoint of the study was total 5-day area-under-the-curve (AUC) equivalence of oral decitabine and cedazuridine and IV decitabine.

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2. Oral decitabine and cedazuridine (ASTX727) is approved in the U.S. and Canada for the treatment of adult patients with myelodysplastic syndromes (MDS), including previously treated and untreated, de novo and secondary MDS with the following French-American-British subtypes (refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, and chronic myelomonocytic leukemia [CMML]) and intermediate-1, intermediate-2, and high-risk International Prognostic Scoring System groups. See U.S. full Prescribing Information: https://www.inqovi.com/pi. See Product Monograph: https://www.taihopharma.ca/documents/31/INQOVI_Product_Monograph.pdf

Syros Announces Encouraging Initial Data from Randomized SELECT-AML-1 Phase 2 Clinical Trial Evaluating Tamibarotene in Combination with Venetoclax and Azacitidine

100% CR/CRi Rate in Patients Treated with Tamibarotene, Venetoclax and Azacitidine Compared to 70% in Patients Randomized to Treatment with Venetoclax and Azacitidine Alone

Triplet Regimen Continues to Demonstrate Favorable Tolerability

Additional Data Expected in 2024

CAMBRIDGE, MA — DECEMBER 06, 2023 (BUSINESS WIRE). Syros Pharmaceuticals (NASDAQ: SYRS), a biopharmaceutical company committed to advancing new standards of care for the frontline treatment of hematologic malignancies, today announced strong and encouraging initial data from its ongoing SELECT-AML-1 Phase 2 trial evaluating tamibarotene, an oral, selective, retinoic acid receptor alpha (RARα) agonist, in combination with venetoclax and azacitidine in newly diagnosed, unfit patients with acute myeloid leukemia (AML) and *RARA* gene overexpression.

"I am highly encouraged by the initial data from the randomized portion of SELECT-AML-1," said Thomas Cluzeau, MD, PhD, Head of Hematology at Nice University Hospital, Côte d'Azur University in France. "Despite the recent advances in treatment for unfit AML patients, there remains a substantial need for options that offer higher response rates and improved overall survival, particularly for the one-third of patients who do not respond to existing standard-of-care. I believe tamibarotene may offer a significant therapeutic advance for the treatment of AML and I am eager to continue enrolling patients in the ongoing SELECT-AML-1 trial."

"These data highlight the potential of tamibarotene to be a cornerstone therapy for newly diagnosed, unfit AML patients with *RARA* overexpression, further demonstrating its differentiated product profile and validating our biologically targeted approach," said David A. Roth, M.D., Chief Medical Officer of Syros. "These results — the first from a randomized, controlled study — demonstrate the potential impact of adding tamibarotene to the standard-of-care, venetoclax and azacitidine and, importantly, are consistent with prior experience. Across multiple clinical trials, we have observed tamibarotene's ability to rapidly deliver clinically relevant activity, with a well-tolerated safety profile, including in a combination setting. We look forward to advancing our comprehensive clinical development program for tamibarotene, with additional data from SELECT-AML-1 and pivotal complete response data from our SELECT-MDS-1 trial in higher-risk myelodysplastic syndrome with *RARA* overexpression expected next year, as we work to deliver profound benefit to patients with hematologic malignancies."

INITIAL DATA FROM SELECT-AML-1 PHASE 2 TRIAL

SELECT-AML-1 is evaluating the safety and efficacy of tamibarotene in combination with venetoclax and azacitidine compared to venetoclax and azacitidine in approximately 80 patients randomized 1:1. The trial is also evaluating the triplet regimen as a salvage strategy in patients in the control arm who do not respond to venetoclax and azacitidine. The primary endpoint of the trial is complete response rate (CR)/complete response with incomplete hematologic recovery (CRi). In December 2022, Syros reported data from the safety lead-in portion of SELECT-AML-1, in which five of six response evaluable patients (83%) achieved CR/CRi.

As of November 13, 2023, 23 newly diagnosed unfit AML patients positive for *RARA* overexpression had enrolled in the randomized portion of the trial, including 19 who were evaluable for response. The median age of the patients for the triplet arm was 77 (ranging from 66–85) and the median age of the patients for the doublet arm was 76 (ranging from 69–84).

Clinical Activity Data

- The primary endpoint (CR/CRi rate), defined in alignment with ELN AML criteria (Dohner 2017 and Bloomfield 2018), was 100% among response evaluable patients (nine of nine) treated with the combination of tamibarotene, venetoclax and azacitidine, as compared to 70% of patients (seven of ten) treated with the control (venetoclax and azacitidine alone).
  - Seven of the nine response evaluable patients (78%) treated with the combination of tamibarotene, venetoclax and azacitidine achieved a CR and two patients (22%) achieved a CRi.
  - Three of the ten response evaluable patients (30%) treated with the control achieved a CR and four patients (40%) achieved a CRi.
- Median time to CR/CRi response was 21 days (ranging from 14–28) among patients treated with the combination of tamibarotene, venetoclax and azacitidine, as compared to 25 days (ranging from 17–56) among patients treated with the control, with the CR/CRi being reached by 100% of patients in the triplet arm by the end of cycle one, compared with 60% of patients in the doublet control arm.

Safety Data

- Consistent with prior clinical experience from the safety lead-in portion of this study, tamibarotene administered in combination with approved doses of venetoclax and azacitidine was generally well tolerated, and the overall safety profile demonstrated no additive toxicities or new safety signals, or evidence of increased myelosuppression compared to treatment with the doublet combination of venetoclax and azacitidine. The majority of non-hematologic adverse events (AEs) were low-grade and reversible,

and rates of serious adverse events (SAEs) were comparable between the study arms.

- Median duration of treatment was 66 days (ranging from 8–188) among patients treated with the combination of tamibarotene, venetoclax and azacitidine, and 75 days (ranging from 7–227) for patients treated with the control. Patients will be followed for duration of response, minimal residual disease (MRD)-negative response, and survival.
- Syros continues to enroll patients in SELECT-AML-1 and anticipates reporting updated data from the trial in 2024.

Syros is also evaluating tamibarotene in combination with azacitidine in the SELECT-MDS-1 Phase 3 clinical trial in newly diagnosed higher-risk myelodysplastic syndrome patients with RARA gene overexpression. Syros expects to complete patient enrollment in SELECT-MDS-1 in the first quarter of 2024 and to report pivotal CR data by the middle of the fourth quarter of 2024.

MDSF is an official author of

Experiences and Support Needs of Caregivers of Patients with Higher-Risk Myelodysplastic Syndrome via Online Bulletin Board in the USA, Canada and UK

Pauline Frank,[1] Anne Olshan,[2] Tracey Iraca,[3] Cindy Anthony,[4] Sophie Wintrich[5], Emma Sasse[1]

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4. Aplastic Anemia and Myelodysplasia Association Canada, King City, ON, Canada
5. MDS UK Patient Support Group, London, UK

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ABSTRACT

Introduction: Patients with higher-risk myelodysplastic syndromes (MDS) face considerable challenges in disease management and often require caregiver support. Reports on the burden of caring for patients with advanced cancer suggest that caregivers receive insufficient support. Our research aimed to identify key challenges for caregivers of patients with higher-risk MDS.

Methods: Online bulletin board is a qualitative research methodology which enables data collection via a web-based platform. A mix of moderator-led discussion guide and interparticipant discussion provides the caregiver insights as online dialogue, which then undergo content analysis to extract key findings.

Results: Sixteen caregivers participated from the USA (n = 5), UK (n = 6) and Canada (n = 5). Content analysis identified the caregiver experience in higher-risk MDS as multifactorial, with seven key categories of caregiver burden: caregiver role and burden, mental health, family dynamics, disease experience, treatment experience, healthcare professional (HCP) interactions and information and education.

Conclusion: There is significant impact and burden on caregivers of patients with higher-risk MDS, which varies depending on disease stage, choice (or lack of choice) of treatments, and the personal situation of the caregiver. Emotional stress occurs mostly at diagnosis/prognosis stage and when told to 'watch and wait', which is amplified when HCPs are perceived to lack knowledge/expertise about MDS. There is a need for better education about MDS for HCPs, patients, caregivers and the general community; a need for improved communication between patients/caregivers and HCPs; and a high unmet need for better mental health and emotional support for both patient and caregiver.

This research has been previously presented as congress abstract/posters accordingly: (i) Pauline Frank, Emma Sasse. Abstract accepted at ASH 2020, Virtual, December 5–8, 2020. https://doi.org/10.1182/blood-2020-138670. (ii) Pauline Frank, Anne Olshan, Tracey Iraca, Cindy Anthony, Sophie Wintrich, Emma Sasse. Poster presented at EHA 2021, Virtual (PB1743) https://library.ehaweb.org/eha/2021/eha2021-virtual-congress/324414/pauline.frank.experiences.and.support.needs.of.caregivers.of.patients.with.html. (iii) Pauline Frank, Anne Olshan, Tracey Iraca, Cindy Anthony, Sophie Wintrich, Emma Sasse. Poster presented at SOHO 2021, Virtual, September 8–11, 2021 (MDS-082). https://doi.org/10.1016/S2152-2650(21)01789-4.

KEY SUMMARY POINTS

WHY CARRY OUT THIS STUDY?

There is significant impact and burden on caregivers of patients with higher-risk myelodysplastic syndromes (MDS). This research aimed to identify key challenges for caregivers of patients with higher-risk MDS.

WHAT WAS LEARNED FROM THE STUDY?

- Caregiver experience in higher-risk MDS is multifactorial.
- Patients/caregivers perceive a lack of knowledge/expertise about MDS in healthcare professionals outside of MDS Centres of Excellence.
- There is a high unmet need for mental health and emotional support for both patients and caregivers, which is not part of standard of care worldwide.

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