

WINTER MDS UPDATE



San Antonio, TX Hybrid Patient & Family Conference March 26, 2022



REGISTRATION FOR THIS CONFERENCE IS AVAILABLE! [CLICK HERE TO REGISTER.](#)
DEADLINE FOR IN-PERSON ATTENDANCE REGISTRATION IS MARCH 2ND

Order your FREE MDS TOOLKIT online:

<https://www.aamds.org/support/mds-toolkit> or call (800) 747- 2820 x2 for our Patient Educator who will assist you in finding an MDS expert and getting your MDS Toolkit



LOOKING FOR A SPECIALIST?

Myelodysplastic Syndromes (MDS) are challenging for both health care providers and patients to diagnose, treat and understand. You need an expert to help you manage your care and you need expert-level advice for managing your disease. You can find an MDS expert on our website:

<https://www.aamds.org/patients/find-a-specialist>

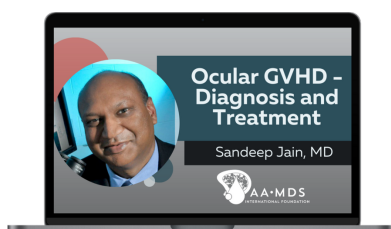
UPCOMING MDS WEBINARS FOR PATIENTS AND CAREGIVERS

AAMDSIF offers free live (and on-demand) webinars for patients and caregivers. A full listing of available webinars can be found on our website (<https://www.aamds.org/education/courses>). Send your suggested topics to help@aamds.org!

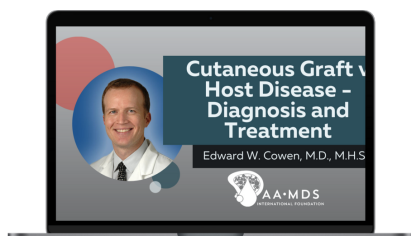
Transplant for Older Patients with MDS



Ocular GVHD - Diagnosis and Treatment



Cutaneous Graft v Host Disease - Diagnosis and Treatment



"GET BUSY LIVING" WITH JOAN POWELL



On Halloween 2014, Joan Powell got a call from her doctor that she was diagnosed with MDS. Her doctor explained to her that the disease is currently incurable.

After some time of grieving and acceptance, Joan became proactive. She began to attend conferences to learn more about the disease and from there, she learned that there were many others like her, who were diagnosed with MDS as well and her journey felt a whole lot less lonely. Today, Joan is a member of the AAMDSIF Patient Education Council as well as a facilitator of the AAMDSIF MDS Support Group.

In this video, she shares her journey through MDS as well as shares her experience and how she's handled MDS in a Q&A that follows her story. Click [here](#) to watch the full video.

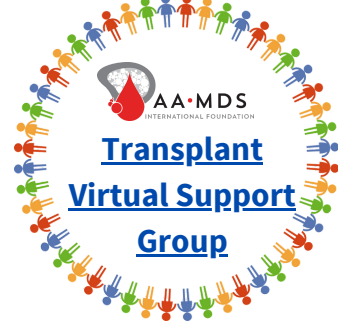
Do you have a story of hope?

Share it with us by contacting Tricia at baker@aamds.org or send a direct message via [Facebook](#), [Instagram](#), or [Twitter](#)

AAMDSIF MDS SUPPORT GROUPS

AAMDSIF HOSTS VIRTUAL SUPPORT GROUPS FOR MDS PATIENTS, FAMILY MEMBERS AND CAREGIVERS. OUR SUPPORT GROUPS ARE POSTED ON OUR WEBSITE AND WE ENCOURAGE YOU TO JOIN THESE UPCOMING OPPORTUNITIES TO

CONNECT:



IMPORTANT CLINICAL TRIALS

Please consult your health care provider about enrolling in clinical trials. For a full description of each trial, please visit www.aamds.org/treatments/clinical-trials.

A STUDY OF APG-115 ALONE OR COMBINED WITH AZACITIDINE IN PATIENTS WITH AML, CMML, OR MDS

This is a two-part study in patients with relapsed/refractory acute myeloid leukemia (AML), chronic myelomonocytic leukemia (CMML), or high risk myelodysplastic syndrome (MDS) that will initially evaluate the safety and tolerability of APG-115 as a single agent in Part 1, followed by a combination of APG-115 + azacitidine in Part 2. Full details are available [here](#).

SELECT-MDS-1, A RANDOMIZED, DOUBLE-BLIND, PLACEBO-CONTROLLED STUDY OF TAMIBAROTENE PLUS AZACITIDINE VERSUS PLACEBO PLUS AZACITIDINE IN NEWLY DIAGNOSED, RARA-POSITIVE ADULT PATIENTS WITH HIGHER-RISK MYELODYSPLASTIC SYNDROME

This study compares the efficacy of tamibarotene (formerly SY-1425) in combination with azacitidine to azacitidine in combination with placebo in participants who are Retinoic Acid Receptor Alpha (RARA) positive, and newly diagnosed with higher-risk myelodysplastic syndrome (MDS), and who have not received treatment for this diagnosis. The primary goal of the study is to compare the complete remission rate between the two treatment arms. Full details are available [here](#).

AAMDSIF does not recommend, endorse, or make any representation about the efficacy, appropriateness or suitability of any clinical trial listed on our website. Pharmaceutical company sponsored content is highlighted only to give additional information about the trial. All trials are listed on <https://clinicaltrials.gov/>

MDS Related Research

Why Patients with Higher-Risk MDS Stop Taking Hypomethylating Agents

Amer Methqal Zeidan, Namita Joshi, Hrishikesh Kale, Wei-Jhih Wang, Shelby Corman, Kala Hill, Tehseen Salimi, Robert S. Epstein

Experts recommend that patients with higher-risk MDS finish 4 to 6 cycles of treatment with the hypomethylating agents (HMAs) azacitidine (Vidaza) or decitabine (Dacogen). But more than a third of patients stop their HMA treatment before they finish 4 cycles or pause their treatment for at least 90 days. When patients don't finish their HMA treatment, they don't survive as long as those who finish at least 4 treatment cycles. These researchers studied the reasons patients stop their HMA treatment early. Read more [here](#)

Combination of Sabatolimab with Azacitidine or Decitabine for Acute Myelogenous Leukemia or High-Risk MDS

Andrew Wei, Jordi Esteve, Kimmo Porkka, Steve Knapper, Elie Traer, Sebastian Scholl, Guillermo Garcia-Manero, Norbert Vey, Martin Wermke, Jeroen Janssen, Rupa Narayan, Sun Loo, Natalia Tovar, Mika Kontro, Oliver Ottmann, Purushotham Naidu, Sema Kurtulus, Elena Orlando, Nidhi Patel, Jessica Makofske, Fei Ma, Na Zhang, Anisa Mohammed, Mikael L. Rinne, Uma Borate, Andrew M. Brunner

Sabatolimab is an experimental treatment that targets TIM-3, a receptor on immune cells and immature leukemia cells. Healthy bone marrow cells don't have TIM-3. By blocking TIM-3, sabatolimab might help the patient's immune cells kill immature leukemia cells in the bone marrow. This study explored the safety and efficacy of the combination of sabatolimab with a hypomethylating agent (HMA), decitabine (Dacogen) or azacitidine (Vidaza), in patients with higher-risk MDS or newly diagnosed AML. Read more [here](#)

The 2021 ASCO/EHA MDS and AML Research Summaries for Patients is now available for download, [here](#)

Blood and marrow transplants (BMT) help people with advanced myelodysplastic syndromes (MDS)

Although BMT is the only known cure for MDS, many people aren't aware of BMT or think that they're too old to have one because of its side effects. Read more [here](#)

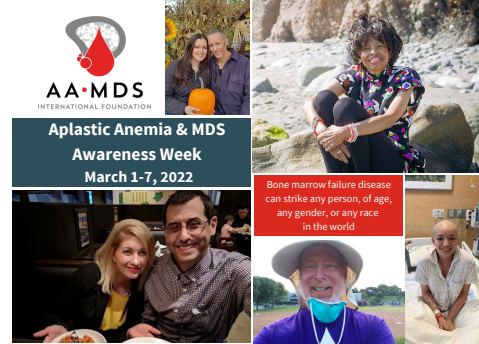
Need help? Please contact us:

Email us at help@aamds.org or call 301-279-7202
www.aamds.org

UPCOMING EVENTS AND CONFERENCES

MARCH 1-6 IS APLASTIC ANEMIA AND MDS AWARENESS WEEK

WE'RE JOINING WITH OUR PATIENTS, FAMILY MEMBERS AND HEALTHCARE PROFESSIONALS TO RAISE AWARENESS ABOUT APLASTIC AND MDS.



UPCOMING MARCH FOR MARROW WALKS

CLICK [HERE](#) FOR MORE INFORMATION AND DETAILS



13TH ANNUAL MARCH FOR MARROW 5K RUN & WALK

SATURDAY, APRIL 2, 2022, 8:00AM



13TH ANNUAL MARCH FOR MARROW 5K RUN & WALK SHORELINE VILLAGE LONG BEACH, CA SATURDAY APRIL 30, 2022



"This run is perfect for new and seasoned runners. It is scenic, flat, and fast."

When I can, I run it in memory of my brother, Garrett."

- Mia Hamm,
US Women's National Soccer Team



UPCOMING CONFERENCES



Register Now [HERE](#)

2022 Patient & Family Conferences



06/18 Seattle, WA

09/24 New Haven, CT

07/23 Memphis, TN

10/22 Miami, FL