



MDS Update

Connecting Patients and Families with News and Expert Opinion

Winter Conference Features Exciting MDS Treatment Updates!

Our Conference Agenda has two MDS-specific sessions including "Understanding Low Risk Myelodysplastic Syndromes (MDS)" and "Understanding Higher Risk MDS (and transition to AML)". Check out the full agenda [here](#) and register for the Conference for full access to live and recorded as well as the MDS Patient Support Group.

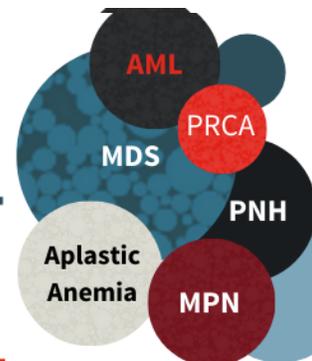
Please note that all sessions are recorded. To gain full access, please register by **November 12, 2021**.



Winter Virtual Patient & Family Conference

November 13, 2021

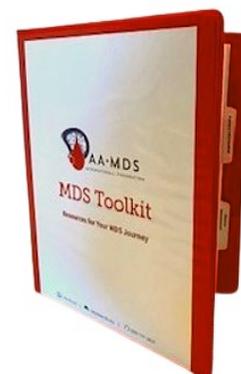
Winter 2021



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>. Order your FREE MDS Toolkit today 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.



Important 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 on our [website](#).

COMMANDS TRIAL: Efficacy and Safety Study of Luspatercept (ACE-536) Versus Epoetin Alfa for the Treatment of Anemia Due to IPSS-R Very Low, Low or Intermediate Risk Myelodysplastic Syndromes (MDS) in ESA Naïve Subjects Who Require Red Blood Cell Transfusions

This is an interventional active-controlled, open-label, randomized Phase 3 study to compare the efficacy and safety of luspatercept (ACE-536) versus epoetin alfa for the treatment of anemia due to IPSS-R very low, low or intermediate risk MDS in ESA naïve subjects who require RBC transfusions. 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. A subset of participants have MDS characterized by an overexpression of the RARA gene. Full details are available on our [website](#).

AAMDSIF MDS Support Groups

AAMDSIF hosts virtual support groups for MDS patients, family members and caregivers. Our support groups are posted on our Support Group [webpage](#) website and we especially encourage you to join these upcoming opportunities to connect:

AAMDSIF Winter Conference MDS Support Group



MDS Support Group
(plus Aplastic Anemia and PNH)



Transplant Support Group



MDS Related Research

[Predicting survival of patients with hypocellular myelodysplastic syndrome](#)

The authors studied a cohort of 253 patients with hypocellular MDS diagnosed at The University of Texas MD Anderson Cancer Center between 1993 and 2007 and a cohort of 1725 patients with hyper-/normocellular MDS diagnosed during the same time period. The results came out that patients with hypocellular MDS presented more frequently with thrombocytopenia ($P < .019$), neutropenia ($P < .001$), low serum β -2 microglobulin ($P < .001$), increased transfusion dependency ($P < .001$), and intermediate-2/high-risk disease (57% vs 42%, $P = .02$) compared with patients with hyper-/normocellular MDS. However, no difference in overall survival was observed between the 2 groups ($P = .28$). For more information on the study, click the link in the headline.

[Evolutionary action score identifies a subset of TP53 mutated myelodysplastic syndrome with favorable prognosis](#)

In a recent study, doctors identified 270 patients with newly-diagnosed MDS or oligoblastic AML (<30% blasts) with ≥ 1 missense TP53 mutation(s) at baseline detected by next-generation sequencing (Fig. 1A). The median TP53 VAF was 33.9 (1–94.4); 165 (61%) had multi-allelic TP53 alterations. Majority were treated with hypomethylating agents (HMA). For more information on the study, click the link in headline.

A Patient's Story: Two Transplants Mean New Life For Derek

When Derek was diagnosed with high-risk Myelodysplastic Syndrome (MDS), his hematologist explained that it may advance to Acute Myeloid Leukemia. The hematologist explained the brief life expectancy and the limited treatment options for these patients. From there, Derek decided to seek further treatment. He discussed the possibility of a stem cell transplant as it provided an opportunity for a longer life. However, after having done the operation, Derek's first transplant had not been successful when it was confirmed by another bone marrow biopsy. The specialists recommended he have a second transplant, myeloablative transplant. This would involve greater risks than the first transplant, due to his already weakened condition, but it was his only hope.

Click [here](#) to read the full story.

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](#).



New 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!

Join us on Friday, November 5th for
"Understanding GVHD" webinar!
1pm EST
Register [here](#)

