

## Summer Conference Features Exciting MDS Treatment Updates!

Our Conference Agenda has three MDS-specific sessions including "Understanding MDS Risk Scores" with Dr. Swapna Thota, "Understanding Lower Risk MDS: What Are My Options?" with Dr. Amer Zeidan and "Managing Higher Risk MDS and AML" with Dr. Eunice Wang. 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](#) on Friday, July 16, 2021 at 4pm ET.

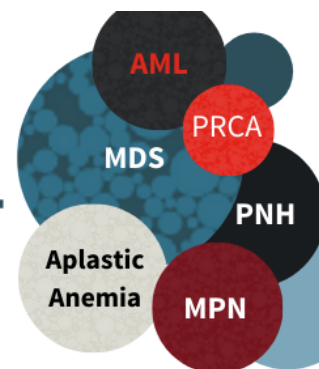
Please note that all sessions are recorded but to gain full access, you need to register no later than July 16, 2021.



## Summer Global Patient & Family Conference

**July 16 & 17, 2021**

Summer 2021



## Please Share Your Perspective

AAMDSIF is currently conducting a unique survey aimed at better understanding the emotional and mental health need of MDS patients and caregivers. We'll use this information to improve our resources and support services and we'll also share the findings with patients, families, and health care providers.

If you're interested in participating in this study, send an e-mail to [hok@aamds.org](mailto:hok@aamds.org) to request a link to the survey, or click [here](#). Any information provided in the survey will be treated with the strictest confidence and will remain entirely confidential. The survey will take about 25 minutes to complete and you will be compensated for your time.

## New MDS Related Research

[Palliative Medicine in MDS: Patients and Caregivers](#) (Desai, Klimek, Wan, Heinberg, Anderson, Bernal, Nelson)

In a recent study of newly diagnosed MDS patients and caregivers, healthcare providers discovered that their term "palliative care" was received negatively by patients and caregivers while "supportive care" got positive responses and yet these two terms generally refer to the same services and supports. While healthcare providers are slowly changing their language, it's helpful for MDS patients, families and caregivers to know that palliative care is supportive care.

[Traipsing Through Muddy Waters: A Critical Review of the MDS/MPN Overlap Syndromes](#)

(Kuykendall, Tokumori, Komrokji)

Understanding the overlap of MDS and MPN is complicated, even for experienced hematologists/oncologists. Next generation sequencing has helped many researchers begin to find new treatment options for patients with MDS/MPNs. In order to help patients, families and caregivers dealing with this diagnosis, we have scheduled an upcoming webinar called "Molecular Genetics of MDS/MPN Overlap Syndrome". You can register [here](#) to reserve your spot.

Research articles are compiled on our website for patients by disease. To read more, go to our [website](#).

## September is National Blood Cancer Awareness Month

We're joining with our patients, family members and healthcare professionals  
to raise awareness about MDS, AML and CLL.

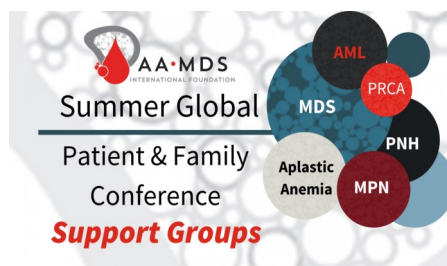
Follow us on [Facebook](#) to learn more!

# 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:

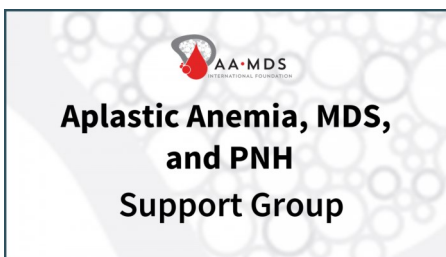
Friday, July 16, 2021  
4pm ET

[AAMDSIF Summer Conference MDS](#)



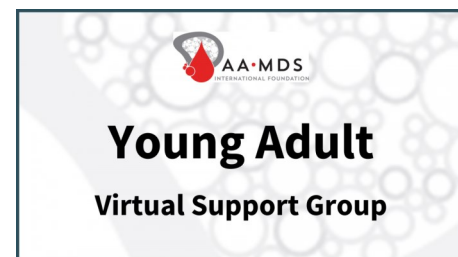
Saturday, July 24, 2021  
10:30am ET

[MDS Support Group](#) (plus Aplastic Anemia and PNH)



Wednesday, July 28, 2021  
6pm ET

[Young Adult Virtual Support Group](#):



## Important MDS Clinical Trials

*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/>. Always seek the advice of your physician or other qualified health care provider with any questions you may have regarding a clinical trial, and never disregard professional medical advice or delay in seeking it because of something you have read on our website.*

### COMMANDS Trial for Very Low, Low or Intermediate Risk MDS Patients

This randomized Phase 3 study compares luspatercept (ACE-536) to epoetin alfa for managing anemia in MDS patients who have not received ESA and who require red blood cell transfusions. The clinical trial, participants are randomized into luspatercept or epoetin alfa and then an open-label treatment period. All patients may receive best supportive care in combination with study drugs. Full details are available on our [website](#).

### Verona Trial for Higher Risk MDS Patients

This randomized Phase 3 study will determine if adding venetoclax to azacitidine in participating higher risk MDS patients improves outcomes. Currently, there are very few treatment options for patients with this diagnosis. Please note that this trial is not open to patients with therapy-related MDS, MDS/MPNs or who have been treated previously with lenalidomide, ATG or cyclosporin. Full details are available on our [website](#).

## A Caregiver's Story: MDS Diagnosis Changes their Lives

When Danielle realized that her fiancé hadn't had a regular checkup, she pushed him to make the appointment. This routine blood draw started their journey through blood draws, a bone marrow biopsy, and finally a diagnosis: Low-Risk MDS with 5q deletion. Read their heartwarming story of love, caregiving, and hope on our website and find out what keeps inspiring this couple to make the most of life. Read it [here](#).

Do you have a story of hope? Share it with us by contacting Tricia at [baker@aamds.org](mailto:baker@aamds.org) or via our [Facebook](#) page.



## 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](mailto:help@aamds.org)!

