



MDS Update

Connecting Patients and Families with News and Expert Opinion

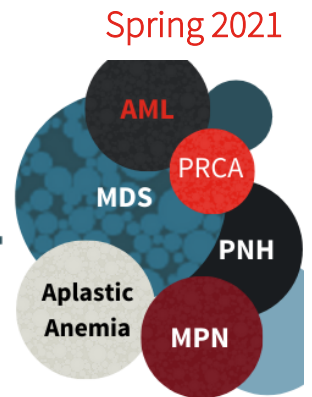
Spring Conference Features Exciting MDS Treatment News!

AAMDSIF is delighted to welcome you to our first virtual conference of 2021 where Dr. Tiffany Tanaka (UC San Diego Health) will discuss the latest treatment options for Low/Moderate Risk MDS patients specific to genetic mutations. Dr. Nathan Punwani (Cedars-Sinai) will give an exciting session on Higher Risk MDS/AML with information on clinical trials and transplant. Dr. Ryotaro Nakamura will answer all of your questions about MDS and transplant in his session. We're also delighted to invite you to attend an **MDS Patient Support Group** at the end of the Conference. Register [here!](#)

All sessions will be recorded for later viewing.



**Spring Virtual
Patient & Family
Conference
April 10, 2021**



EHA/ASCO Research Update: Not All MDS Patients Get Complete Diagnosis

Disparities in Diagnostic Evaluations to Confirm MDS (Mukherjee, Dong, Statler, Koroukian)

In a recently published abstract, investigators found that only **69% of MDS patients** received a complete diagnostic evaluation which includes a bone marrow biopsy and testing for changes in genes and chromosomes. After looking at more than 45,000 patient records, the investigators found that patients over the age of 85, women of all ages, those who identify as Black and those who are not transfusion-dependent were less likely to receive a complete diagnostic evaluation. Review the latest in research here: <https://www.aamds.org/education/patient-guides-and-fact-sheets>

It's very important for all MDS patients to get a complete diagnostic evaluation by a qualified hematologist/oncologist. You can find a specialist on the AAMDSIF website at <https://www.aamds.org/patients/find-a-specialist> or by calling us at (800) 747-2820 x2 for a referral.

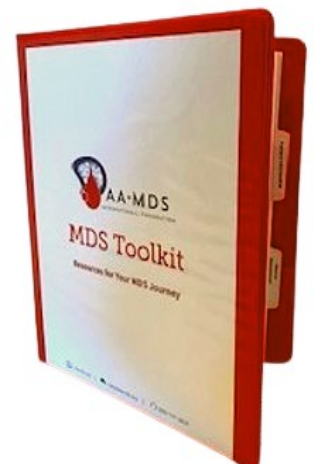
AAMDSIF Provides MDS Expertise and Access to Experts



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> and 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.



Save the Date: April 21, 2021 is World AML Awareness Day!

We're joining with our patients, family members and healthcare professional to raise awareness about AML secondary to MDS. Wear red and black and tag us in a selfie on social media. #KnowAML

March for Marrow California Virtual Walk and 5K Kicks Off on Saturday, April 24, 2021
Sign up today at www.marchformarrow.org

AAMDSIF Adds MDS, Caregiver, Pediatric Parent Support Groups

Thanks to input from our patients, family members and caregivers, AAMDSIF has expanded our virtual support groups to include monthly opportunities for MDS, PNH, Aplastic Anemia, Pediatric Parents, Transplant Patients, Caregivers, Bereavement, Young Adults (18—30) and over the summer of 2021, we're adding a Teen Support Group (13—17) and a GVHD Group. It's so important to be able to talk to other patients like you and these sessions are designed to help you cope with your disease journey. For a complete listing of upcoming support groups, visit our website: <https://www.aamds.org/support/community-events/support-groups> or you can call (800) 747-2820 x2 or send an email to help@aamds.org.

Please note that very few support groups have returned to in-person gatherings due to the ongoing pandemic. We are hosting virtual connection opportunities to keep everyone safe.

**Answers
Support
Hope**



Patient Support Group

Important MDS Clinical Trials

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

Imetelstat (GRN163L) Study of Patients with Low or Intermediate Risk MDS

Phase 2/3 study to evaluate the efficacy and safety of imetelstat in transfusion-dependent participants with low or intermediate-1 risk MDS that is relapsed/refractory to erythropoiesis-stimulating agent (ESA) treatment.

Study of SY-1425 + Azacitidine of Patients with Higher Risk MDS

Phase 3 study to evaluate the effectiveness of this novel agent in Higher Risk MDS patients with the RARA gene.



AAMDSIF is grateful for the many patients, families, caregivers and friends who have made generous investments in the work of the Foundation, including our research grants. To help us continue the search for a cure and to provide answers, support and hope for patients across the globe, please consider making a donation today.

Donations can be securely made online at www.aamds.org/donate, by calling (800) 747-2820, or by sending a check to AAMDSIF at 4330 East West Highway, Suite 230, Bethesda, MD 20814.

New MDS Webinars for Patients and Caregivers

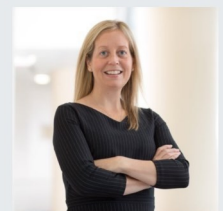
AAMDSIF offers free live (and on-demand) webinars for patients and caregivers. A full listing of available webinars can be found on our website (<https://www.aamds.org/education/courses>).

Intimacy and Bone Marrow Failure



Tanya Bass, MS, Med, CHES, CSE
North Carolina Central University
Independent Consultant/Training/Educator

ASH 2020: MDS Updates



Hetty Carraway, MD
Taussig Cancer Institute - Cleveland Clinic