



# MDS Update

Connecting Patients and Families with News and Expert Opinion

Registration will be available soon!

Our 2022 conferences will be hybrid - both in person and streamed live.



## Save The Date!

### 2022 Patient & Family Conferences

03/26

San Antonio, TX

06/25

Seattle, WA

07/16

Memphis, TN

09/24

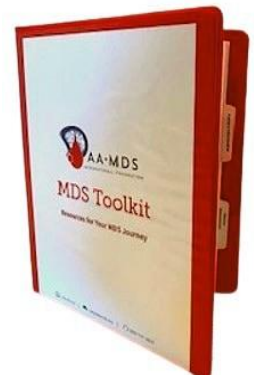
New Haven, CT

10/22

Miami, FL



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.



## MDS Related Research

### Biologic Assignment Trial of Reduced-Intensity Hematopoietic Cell Transplantation Based on Donor Availability in Patients 50-75 Years of Age With Advanced Myelodysplastic Syndrome

There is significant survival advantage in older subjects with higher-risk MDS who have a matched donor identified and underwent reduced-intensity HCT, when compared with those without a donor. HCT should be included as an integral part of MDS management plans in fit older adults with higher-risk MDS.

Learn More: <https://ascopubs.org/doi/10.1200/JCO.20.03380>

### Chronic Graft-versus-Host Disease, Nonrelapse Mortality, and Disease Relapse in Older versus Younger Adults Undergoing Matched Allogeneic Peripheral Blood Hematopoietic Cell Transplantation: A Center for International Blood and Marrow Transplant Research Analysis

The effect of chronic graft-versus-host disease (cGVHD) on the risk of non-relapse mortality (NRM) and relapse has not been specifically studied in older adults, who are increasingly undergoing allogeneic hematopoietic cell transplantation (alloHCT) and surviving long-term to develop cGVHD. In this Center for International Blood and Marrow Transplant Research analysis, they tested our hypothesis that the risk of NRM was higher with the development of cGVHD, particularly among older adults (≥60 years).

Learn More: <https://www.sciencedirect.com/science/article/pii/S2666636721012938?via%3Dihub>

## We Need Your Email!

Log onto <https://www.aamds.org/sign-up> to subscribe and learn more about your or your loved one's disease and our community!

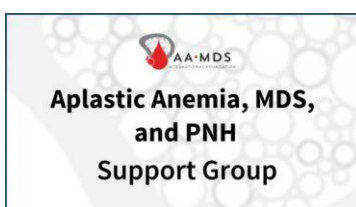
## AAMDSIF MDS Support Groups

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

MDS Support Group

MDS, Aplastic Anemia and PNH Support Group

Transplant Support Group



## Important Clinical Trials

Please consult your health care provider about enrolling in clinical trials.

### 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 [here](#).

### 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](#).

*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.*

## A Patient's Story: MDS—My Story...so Far!

Barry Parnas was diagnosed with MDS in 2010, but didn't start experiencing the symptoms until 8 years later when his hemoglobin was about 6.6. His physician then told him that if he did not receive a BMT he would live at most 12 months. After his procedure, he had received aggressive myeloablative induction therapy as it was the best option to avoid relapse. He had some kidney and infection complications in the hospital that kept him in 2-3 weeks longer than usual. During his time there, he lived in isolation until the last two weeks when he could walk the halls and saw progress of getting stronger. Today, Barry can walk half a mile with a computer in his backpack and no shortness of breath.

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](mailto:baker@aamds.org) or send a direct message via [Facebook](#), [Instagram](#), or [Twitter](#).



## MDS Webinars for Patients and Caregivers On-Demand

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>). Our webinar series will start up again in

[Ask The MDS Expert](#)

[Molecular Genetics of  
MDS/MPN Overlap  
Syndrome](#)

[Living With MDS: A  
Patient Panel  
Discussion](#)

[Hereditary MDS](#)


**Ask The MDS Expert**




**Jason Harold Mendelsohn, MD, PhD**  
Assistant Professor of Oncology  
PhD  
Wilentz Cancer Center



**Molecular Genetics  
of MDS/MPN Overlap  
Syndrome**



**Anthony M. Hunter, MD**  
Assistant Professor  
Eisenhower School of Medicine  
Wendy Cancer Institute



**Living With MDS a  
Patient Panel  
Discussion**



**Hereditary  
MDS**



**Lucy A. Godley, MD, PhD**  
Hopflra Foundation Professor of Medicine  
and Human Genetics  
UChicago Medicine

