

## Join Us!

### Seattle, WA

**June 18, 2022**



### The 9th Seattle Patient Conference

Registration for this conference is available! Click [Here](#) to register for in-person and virtual attendance.

**DEADLINE FOR IN-PERSON ATTENDANCE REGISTRATION IS MAY 18TH**

### Memphis, TN

**July 23, 2022**



### Patient & Family Conference

Registration for this conference is available! Click [Here](#) to register for in-person and virtual attendance.

**DEADLINE FOR IN-PERSON ATTENDANCE REGISTRATION IS JUNE 24TH**

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

#### ASH 2021 Updates: MDS and Secondary AML



#### What's My Doctor Thinking? Treating Secondary AML



#### Genetic Testing for Bone Marrow Failure Diseases



### "My 12-Year Battle With MDS"

**By Jane Biehl, PhD**



Jane has been on a 12-year journey with MDS. Since her diagnosis in 2017, she's experienced extreme drops in her hemoglobin, but was prescribed several drugs such as Luspatercept and received Procrit and Zarxio shots regularly. Although Jane is battling MDS and figuring the changes to her new life on a day-to-day basis, one thing she learned is the importance of patients doing their own research. Read more about Jane's twelve year journey and advice for MDS patients [here](#).

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](#)

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>

## 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](http://www.aamds.org/treatments/clinical-trials).

### STIMULUS MDS-US : SABATOLIMAB ADDED TO HMA IN HIGHER RISK MDS

**This is a single-arm, nonrandomized, open-label, Phase II multicenter study of intravenous MBG453 (sabatolimab) added to hypomethylating agents (HMA) of investigator's choice (IV/SC/ Oral) in adult participants with intermediate, high or very high risk myelodysplastic syndrome (MDS) as per IPSS-R criteria. The study will assess the safety and efficacy of sabatolimab (investigational drug) in combination with an HMA. The study will enroll approximately 90 participants in the United States. Full details are available [here](#).**

### A STUDY OF APG-2575 IN COMBINATION WITH AZACITIDINE IN PATIENTS WITH ACUTE MYELOID LEUKEMIA (AML)

**This is a Phase Ib/II, open-label, multi-center study evaluating the safety, tolerability, efficacy and pharmacokinetics (PK) of APG-2575 in combination with azacitidine in the patients with AML or MDS/CMML. The study consists of dose escalation (Part I) and dose expansion phase (Part II). 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

### ■ Real-world experience with luspatercept and predictors of response in myelodysplastic syndromes with ring sideroblasts

*Faiqa Farrukh, Deandra Chetram, Aref Al-Kali, James Foran, Mrinal Patnaik, Talha Badar, Kebede Begna, Christopher Hook, William Hogan, Kristen B. McCullough, Abhishek Mangaonkar, Rong He, Naseema Gangat, Ayalew Tefferi*

Myelodysplastic syndromes with ring sideroblasts (MDS-RS) is a subcategory of MDS with  $\geq 15\%$  (or  $\geq 5\%$  in the presence of SF3B1 mutation) of bone marrow erythroid precursors; additional diagnostic criteria include the absence of  $\geq 5\%$  bone marrow or  $\geq 1\%$  peripheral blood myeloblasts, Auer rods, and diagnostic criteria for MDS with isolated del(5q). Prognosis in MDS-RS is more favorable than other MDS subtypes with estimated median survival of 46 months and a relatively low risk of leukemic transformation. Currently available drugs in MDS-RS do not modify the natural history of the disease and are primarily directed at anemia and include erythropoiesis stimulating agents (ESAs), lenalidomide, hypomethylating agents (HMAs), and luspatercept. Read more [here](#).

### ■ Failure to reach hematopoietic allogeneic stem cell transplantation in patients with myelodysplastic syndromes planned for transplantation: a population-based study

*C. Lindholm, E. Olofsson, M. Creignou, L. Nilsson, H. Gravdahl Garelius, J. Cammenga, P. Ljungman, E. Ejerblad, M. Tobiaasson*

The only potential cure for patients with myelodysplastic syndrome (MDS) is allogeneic hematopoietic stem cell transplantation (HCT). However, a proportion of patients who are HCT candidates do not finally get transplanted. This population-based study aimed to characterize HCT candidates were attempting to reach HCT fail and to identify causes and risk factors for failure. Read more [here](#).

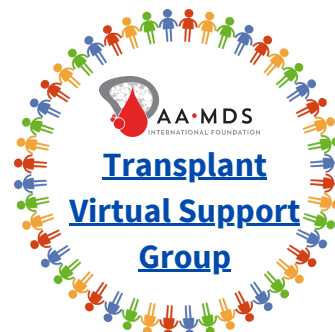
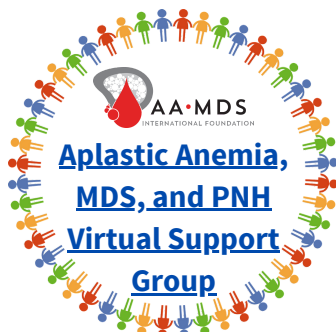
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Email us at [help@aamds.org](mailto:help@aamds.org) or call 301-279-7202  
[www.aamds.org](http://www.aamds.org)

# UPCOMING EVENTS AND CONFERENCES

## 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:



**March for Marrow! Coming to a city near you!**

**Save the dates:**

**Michigan: August 28, 2022 at Bald Mountain State Park**

**Virginia: September 18, 2022 at Bluemont Park**

To learn more or set up your own event, contact Desiree Ruiters at [ambassadors@aamds.org](mailto:ambassadors@aamds.org) or call 301-279-7202 ext 105.



## Register Now

## 2022 Patient & Family Conferences



**Empowering Every Patient**

03/26 San Antonio, TX 06/18 [Seattle, WA](#)

07/23 [Memphis, TN](#) 09/10 [Buffalo, NY](#) 10/22 [Miami, FL](#)