



SUMMER MDS UPDATE

Hybrid Patient & Family Conferences

Empowering Every Patient

Join Us!

Buffalo, NY

September 10, 2022

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



Miami, FL

October 29, 2022

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



INFORMATION

Patient stories provide hope and support to others diagnosed the MDS. In this patient panel discussion, hear how Joan Powell and Maureen Ratliff have battled MDS.

Click [here](#) to tune in.

If you would like to share your story, please contact us, help@aamds.org.



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.

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](#).

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 [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

■ **Innate immune pathways and inflammation in hematopoietic aging, clonal hematopoiesis, and MDS**

Jennifer J. Trowbridge, Daniel T. Starczynowski

There is an imminent need to develop new therapeutic strategies to ameliorate disorders of hematopoietic aging, including clonal hematopoiesis and myelodysplastic syndrome (MDS). Cell-intrinsic dysregulation of innate immune- and inflammatory-related pathways as well as systemic inflammation have been implicated in hematopoietic defects associated with aging, clonal hematopoiesis, and MDS. Read more [here](#).

■ **Distinguishing AML from MDS: a fixed blast percentage may no longer be optimal**

Elihu Estey, Robert P. Hasserjian, Hartmut Dohner

Patients with acute myeloid leukemia (AML) have conventionally received more intense therapy than patients with myelodysplastic syndrome (MDS). Although less intense therapies are being used more often in AML, the dichotomy between AML and MDS remains, with the presence of $\geq 20\%$ myeloblasts in marrow or peripheral blood generally regarded as defining AML. Read more [here](#).

Need help? Please contact us:

Email us at help@aamds.org or call 301-279-7202


DOCUMENTS

Emergency Health Information Card

Not all healthcare professionals or emergency responders will understand your rare diagnosis and unique needs. AAMDSIF has created an emergency health information card that communicates to others what they need to know about you to help you during a medical emergency.

Download cards and instructions [HERE](#).

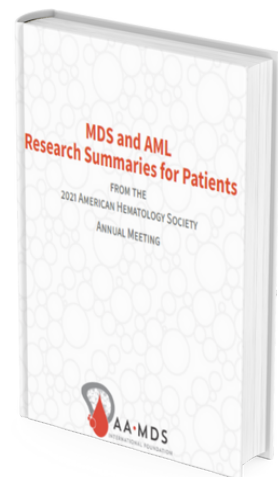
Medical Conditions	Emergency Medical Card	Emergency Contacts
Notes Check all that apply: <input type="checkbox"/> Low red cell count <input type="checkbox"/> Low platelet count <input type="checkbox"/> Low white cell count <input type="checkbox"/> Hemolysis <input type="checkbox"/> Infection <input type="checkbox"/> Petechiae/bruising <input type="checkbox"/> Transfusion-dependent <input type="checkbox"/> Immunocompromised <input type="checkbox"/> Blood Clots <input type="checkbox"/> Other	Name: Street Address: City, State, Zip: Phone: Country: Language Spoken: Gender: Ethnicity: Organ Donor: Height: Weight: Blood Type: Last Updated: 	Name & Number Relationship:
	Medications	
	Health Care Team	
	Drug Allergies	
	Covid Vaccination	
	Other Allergies	
	Date: 1st Vaccine Type: Date: 2nd Vaccine Type: Date: Booster 1 Type: Date: Booster 2 Type:	

Aplastic Anemia	MDS	PNH
Aplastic anemia is an autoimmune blood disease caused by the destruction of blood-forming stem cells in bone marrow by the immune system. It causes the bone marrow to produce too few of all types of blood cells: red cells, white cells, and platelets.	Myelodysplastic syndrome (MDS) is a group of disorders in which bone marrow cells do not develop into mature blood cells. MDS stops the bone marrow from making healthy blood cells (red blood cells, white blood cells, and/or platelets). MDS is a blood cancer.	Paroxysmal nocturnal hemoglobinuria (PNH) is a rare blood disease that causes red blood cells to break apart causing hemolysis. PNH happens because of a change (mutation) in the PIG - A gene of a single stem cell in the bone marrow.
Notes	Notes	Notes
PRCA	AML	Emergency Card
Pure red cell aplasia (PRCA) is a very rare condition characterized by an absence of red cell precursors (reticulocytes) in the marrow and a low red blood cell count. The amounts of white blood cells and platelets remain normal.	Acute myeloid leukemia (AML) is a fast-growing blood cancer. It occurs when the bone marrow begins to make white cells that have not yet completely matured. The bone marrow may also make abnormal red blood cells and platelets.	Name:  www.aamds.org
Notes	Notes	

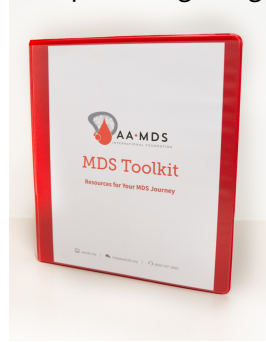
MDS/AML Research Summary for Patients

This publication offers summaries of selected abstracts presented at the December 2021 Meeting of the American Hematology Society. It provides new and updated information about new research into the diagnosis, treatment, and prognosis of bone marrow failure diseases with a deep focus on Myelodysplastic Syndromes (MDS) and Acute Myeloid Leukemia (AML) secondary to MDS.

Click [here](#) to access the research summaries.



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>

UPCOMING EVENTS

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!

Ask the Transplant Expert



Genetic Testing for Bone Marrow Failure Diseases

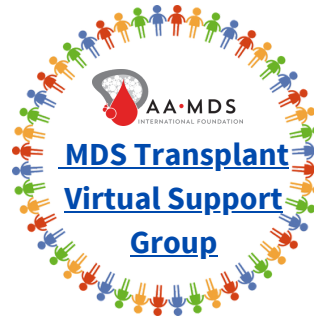
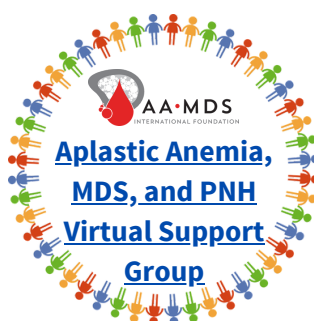
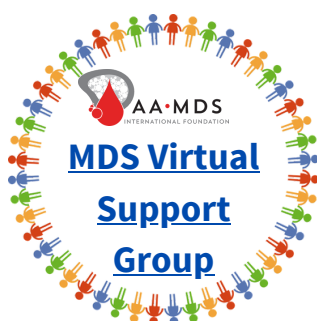


VEXAS Syndrome (On-Demand)



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
AA-MDS INTERNATIONAL FOUNDATION

Find a March for Marrow Event Near You



[Detroit - August 28, 2022](#)

[Virginia - September 18, 2022](#)

[New Jersey - September 25, 2022](#)

[Nevada - October 15, 2022](#)