



Foundation Update

January 2021

For you in this issue: Patient & Family Conference Schedule | March for Marrow Kick-Off! | New COVID-19 Fact Sheet | Virtual Support Groups | Aplastic Anemia Clinical Trial | PNH Treatment News | New Research Grantees | MDS UPDATE

A graphic divided into four quadrants, each representing a conference date and featuring a seasonal background image. The top-left quadrant shows pink tulips and the date "April 10". The top-right quadrant shows a bright sun and the date "July 16-17". The bottom-left quadrant shows autumn trees and the date "September 11". The bottom-right quadrant shows a mug and a sweater and the date "November 13". Overlaid in the center is the text "Virtual ▪ 2021 Patient & Family Conferences ▪".

April 10

July 16-17

September 11

November 13

▪ *Virtual* ▪

2021 Patient & Family Conferences

Each Patient & Family Conference in 2021 will have different speakers and topics, so be sure to save these dates for these Virtual Sessions! Registration will be live here soon:

<https://www.aamds.org/education/conferences/patients>



Planning has begun for the 2021 Virtual March for Marrow Events!

Kick-off is the week of March 1-7, 2021. Join us as we walk virtually and safely in our communities to raise awareness for aplastic anemia, MDS, PNH, and related bone marrow failure diseases.

Find out more and register today!

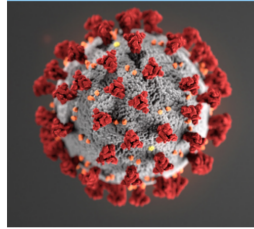
- [Global Kick-Off Event](#) – Registration open now! – March 1-7, 2021
- [Texas March for Marrow Walk and 5K Run](#) – March 27 - April 3, 2021
- [California March for Marrow Walk and 5K Run](#) – April 24 – May 1, 2021

Stay tuned! More events are coming! If you'd like to get involved, email Julie [here](#).

Thank You!

To everyone who helped us offer support to patients and families for 2020 and beyond!

NEW COVID-19 INFORMATION



COVID-19 Guidance for Patients January 2021 now includes **Vaccine** information!

Download this fact sheet [HERE](#)

Virtual Support Groups



New Support Groups are all VIRTUAL. Encourage your peers and be encouraged as well. Share your stories and your questions with others who are living through the same. You can register now for the groups below, and watch your email for more!

Bereavement Support Group January 19 Register here:

<https://aamdsif.salsalabs.org/january2021aamdsifbereavementsupportgroup/index.html>

PNH Support Group January 29 Register here:

<https://aamdsif.salsalabs.org/january2021pnhpatientsupportgroup/index.html>



The primary objective of this study is to assess the safety and tolerability of REGN7257 in patients with severe aplastic anemia (SAA) that is refractory to or has relapsed while on standard of care immunosuppressive therapy (IST). An additional primary objective (for Part B only) is to evaluate the clinical efficacy of REGN7257 in IST-refractory/relapsed patients.

[Find out more about this Clinical Trial](#)



PNH Treatment

We are excited to share important updates with you regarding the clinical development of our investigational therapy, pegcetacoplan, for the treatment of paroxysmal nocturnal hemoglobinuria (PNH). (Please read full article by clicking the button below.)

[Read the Article](#)

2020 Grant Awards Announced!

For 31 years, AAMDSIF has provided research grants totaling over \$5 million to an international group of more than 90 researchers to help advance the understanding and treatment of aplastic anemia, myelodysplastic syndromes (MDS), and paroxysmal nocturnal hemoglobinuria (PNH).

These two-year grants have contributed to new insights into the causes and therapeutic approaches for these diseases.



Audrey Lasry, PhD

New York University School of Medicine

Research Project: Single cell mapping of bone marrow microenvironment during MDS to AML transition [MORE](#)



Valentina Giudice, MD

University of Salerno

Research Project: Low-density granulocytes and neutrophil extracellular traps in AA and MDS [MORE](#)

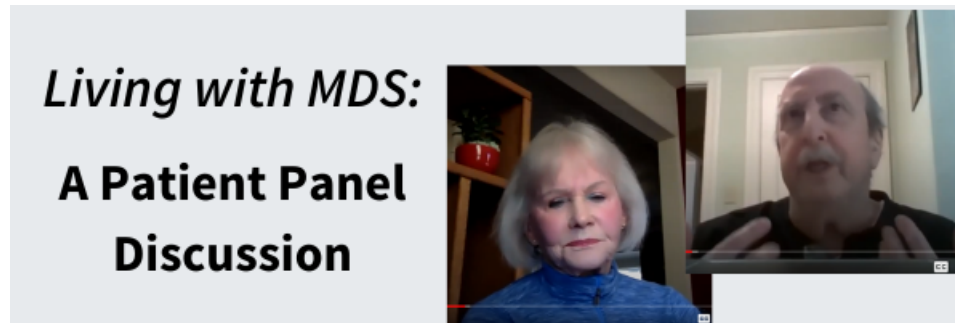
MDS Update

Upcoming MDS Webinar:

- March 8, 2021: [ASH 2020 Updates for MDS and AML](#) (@3pm ET)

More are being scheduled for 2021! Watch your email for notices.

Also for MDS Patients:



Did you miss this patient panel discussion? You're not too late! You can hear about their experiences in this recently recorded session:

<https://www.aamds.org/webinar-recording/living-mds-patient-panel-discussion>

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