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# Foundation Update

## July 2021



March for Marrow  
**DETROIT**  
Virtual Walk and 5K

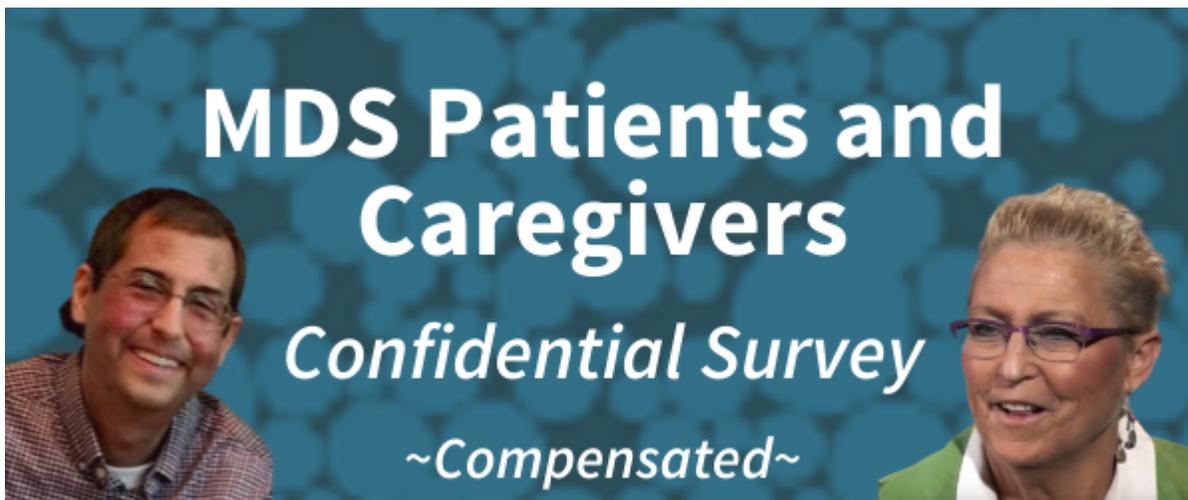


# Tartan Trailblazers

Thanks to technology - we can support the patients and families served by AAMDSIF by registering to walk in our Virtual Event or simply by donating.

Register Yourself or Your Team Now!

[Sign Up](#)



AAMDSIF is currently conducting a **unique survey** aimed at better understanding the emotional and mental health need of MDS patients and caregivers. We'll use this information **to improve our resources and support** services and we'll also share the findings with patients, families, and health care providers.

If you're interested in participating in this study, send an e-mail to [hok@aamds.org](mailto:hok@aamds.org) to request a link to the survey, or start [here](#). Any information provided in the survey will be treated with the strictest confidence and will remain **entirely confidential**. The survey will take about **25 minutes** to complete and you will be **compensated** for your time.



**Global  
PNH Patient  
Registry**

Have you been wondering how to **get involved** with PNH research but did not know where to start? Here's your chance! **Check out** the **Global PNH Patient Registry** at [pnh.iamrare.org](http://pnh.iamrare.org)

# cure®

EDUCATED PATIENT® LEUKEMIA  
SUMMIT

**Saturday, July 31, 2021 | 11:00 AM – 4:00 PM ET | 8:00 AM – 1:00 PM PT**

Join AAMDSIF at the CURE® Educated Patient® Leukemia Summit to be held on July 31, 2021 starting at 11am ET, 8am PT. This virtual program is an opportunity to connect with **leukemia experts** and advocacy group speakers who will empower your cancer journey. The MDS session will feature AAMDSIF Medical Advisory Board members **Dr. Guillermo Garcia-Manero** of MD Anderson Cancer Center and **Dr. Romi Komrokji** of the Moffitt Cancer Center.

**Reserve** your virtual seat and interact online with fellow patients, survivors, caregivers and healthcare professionals. [Learn more & register today!](#)

## *On Vacation?*



Are you on vacation?

No matter your location, AAMDSIF is ready to provide you with answers, support, and hope. Please join us in helping patients and families just like you and yours with your gift [today!](#)

I want to help!



If you would like to be in a **safe place** to talk about what you are going through, or if you would like to encourage others, please check out the Virtual Support Groups [HERE](#). **Together, we are strong!**

**Current schedule:**

Sat, 07/24/2021 - 10:30am (EDT) [Aplastic Anemia, MDS, and PNH Virtual Support Group](#)

Wed, 07/28/2021 - 6:00pm (EDT) [Young Adult Virtual Support Group](#)

**Find webinars with speakers like these, plus patient panelists!**



**Here are the next All-New Webinars for you!**

All Times EDT-US

Thu, 07/29/2021 - [Living with MDS: A Patient Panel Discussion](#)

2:00pm (EDT)

Thu, 08/05/2021 - 2:00pm (EDT)      [Living with a Pediatric Bone Marrow Failure Disease: a Parent Panel Discussion](#)

Mon, 09/13/2021 - 3:00pm (EDT)      [Molecular Genetics of MDS/MPN Overlap Syndromes](#)



(COMMODORE 1) A Study Evaluating The Efficacy And Safety Of Crovalimab Versus Eculizumab In Adult And Adolescent Participants With Paroxysmal Nocturnal Hemoglobinuria (PNH) Currently Treated With Complement Inhibitors

(COMMODORE 2) A Phase III Study Evaluating The Efficacy And Safety Of Crovalimab Versus Eculizumab In Adult And Adolescent Participants With Paroxysmal Nocturnal Hemoglobinuria (PNH) Not Previously Treated With Complement Inhibitors

[Check Criteria Here](#)

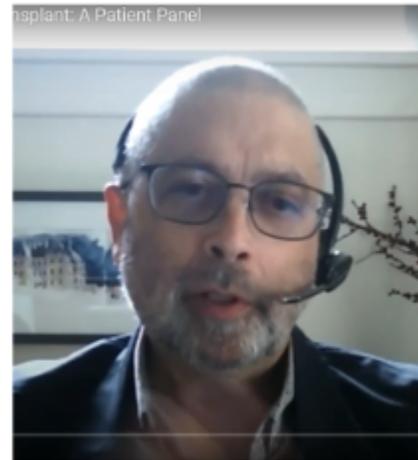
[Check Criteria Here](#)

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/>. 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.

# MDS Update



## **GVHD:** A Patient Panel Discussion *Recording*



This is a great **webinar** for people who are dealing with **graft vs host disease** (GVHD) post-transplant for a bone marrow failure disease, those who are **providing care to** someone with GVHD, and patients **considering transplant** who want to more about living with GVHD. Watch on-demand here:

<https://www.aamds.org/webinar/living-gvhd-transplant-patient-panel-discussion>

## **Podcast Episode:**

MDS Treatment, Inoqvi:  
Dr. Amer Zeidan Explains  
the Use of this Treatment

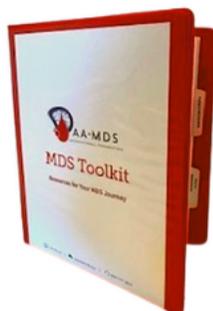


The recently approved hypomethylating treatment, Inoqvi, is a daily oral version of two IV or subcutaneous medications. Listen to Dr. Amer Zeidan of

Yale Cancer Center explain which MDS patients could qualify, and what it means for their treatment [HERE](#).

## MDS Toolkit

Download Yours Today



Download or order your print copy at the button below:

MDS Toolkit

A final thought:

All of our conferences, webinars, educational opportunities, and patient support are made possible from gifts by people like you, friend. Your donation will help us reach more patients and families.

Yes, I'll Help!

Share This



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### **Aplastic Anemia and MDS International Foundation**

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3012797202 | [help@aamds.org](mailto:help@aamds.org)

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