Foundation Update
September 2020

For you in this issue:

Fall Patient & Family Conference | PNH Week | New Webinars | Refreshed MDS Toolkit is ready! | Clinical Trial | MDS Survey | What is INOQVI?

Fall Virtual Patient & Family Conference

October 3, 2020 ~ 9:00 am to 4:00 pm EDT

Sessions:

- What Caused My Bone Marrow Failure Disease: Acquired vs Genetic
- What's New in PNH? New Treatment Options and Clinical Trials
- Understanding MDS Mutations and Risk Scores
- Aplastic Anemia: Transplant vs Non-Transplant Treatment Options
- Improving the Quality of Your Life: Survivors, Caregivers and Friends
- Patient Panel Discussions: Candid Conversations about Life with Bone Marrow Failure
- How to be a Survivor
- Patient Support Groups (concurrent)

Register NOW
We're Virtual!

Join the virtual walk on October 3rd to support patients fighting PNH and related bone marrow failure diseases!

Please take a minute to post your photos from 2019 or previous walks on our Facebook page, and be sure to tag @aamdsif or #MarchforMarrow!

Register to Join us Virtually!

Final Webinars in September

- September 24, 2020: Ask a PNH Expert: Q & A for Patients and Families (@ 4 pm EDT, GMT-4)
- September 30, 2020: New and Emerging Therapies for MDS (@ 3 pm EDT, GMT-4)

Webinars Coming in October:
October 7, 2020:  [Long Term Effects of Stem Cell Transplantation](@ 2:30 pm EDT)
October 14, 2020:  [Advances in Treating High-Risk MDS and AML](@ 2 pm ET)
October 15, 2020:  [Sweet Syndrome and MDS: What's the Connection?](@ 2:30pm EDT)
October 27, 2020:  [What is Chemo Brain? Diagnosis and Treatment for Bone Marrow Failure Disease Patients](@ 1:30 pm ET)
October 28, 2020:  [Diagnosis and Management of Bronchiolitis Obliterans Syndrome After Transplant](4 pm ET)

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**MDS Toolkit**

A resource to help patients manage their MDS journey

These resources will help you learn about all aspects of MDS and manage your health care. Included: printable patient information pages about disease basics, MDS risk level, treatment options, managing side effects, and preparing for your medical appointments.

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**Spotlight Clinical Trial**

- Recruiting Opens Aug 21
- Relapsed/Refractory Severe Aplastic Anemia

US and France Only:
MDS with TP53 Mutation? This clinical trial might be the one for you! Please follow the link for more information.

MDS Patients and Caregivers: Would you please help others by taking this survey - US Residents

MDS New Treatment: INOQVI

Have you heard about INOQVI?

Dr. Amer Zeidan anticipates your questions and explains in this recent podcast. Listen here: [https://www.aamds.org/podcast/mds-treatment-inqovi-dr-amer-zeidan-explains-use-treament](https://www.aamds.org/podcast/mds-treatment-inqovi-dr-amer-zeidan-explains-use-treament)