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Foundation Update
April 2021

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Thank you!
Volunteers

April 18-24 is Volunteer Appreciation Week! We'd like to extend our sincerest thanks to all who have helped the bone marrow failure community through your efforts with AAMDSIF!
Aplastic Anemia, Myelodysplastic Syndromes, and Myeloproliferative Neoplasms: The 8th Seattle (Virtual) Patient Conference

Saturday, June 26, 2021

Registration is open for this VIRTUAL conference!

We're partnering with Fred Hutchinson Cancer Center to bring you expert perspectives on bone marrow failure diseases, diagnosis, and treatments. Use the link below to discover all the topics for discussion!

Register for June 26th Conference

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Upcoming Webinars

Here are the next All-New Webinars for you!

All Times EDT-US

Friday, April 23, 2021 - 2:00 pm  Intimacy and Bone Marrow Failure
Tuesday, April 27, 2021 - 2:00 pm  Haploidentical Transplant for MDS

Monday, May 10, 2021 - 11:30 am  Hereditary MDS
Wednesday, May 12, 2021 - 2:30 pm  Combination Therapies in Relapsed/Refractory AML
Thursday, May 20, 2021 - 12:00 pm  ASH 2020: MDS Updates
Live Video Presentation on **Thursday, May 6th at 10:00 AM EDT**

Join expert clinicians, a patient advocate, and a patient for “Establishing Goals of Therapy While Managing Myelodysplastic Syndromes,” an interactive discussion of MDS and potential treatment approaches.

This hour-long educational session taking place at 10:00 AM EDT on Thursday, May 6. Register [HERE](#)!

**Life Interrupted – Nick’s Fight Against Aplastic Anemia**

From baseball, to transplant, to pitching again!

Read Nick’s amazing Story of Hope [HERE](#)
Our Walks are Gold!

Thank you to the 2021 March for Marrow National Sponsors
Help make this event special -- Sign up to participate in the Virtual March for Marrow California, 5K Run and Patient and Family Walk!

Gather your friends and family to walk as a team; everyone is welcome to participate in the virtual event.

Dates: April 24 – May 1, 2021

Location: Anywhere! You can walk with us in your neighborhood, on a treadmill, or donate and sleep in!

Time: Kick-Off Event on April 24th at 9:00 AM PST and closing program on May 1 at 9:00 AM PST

Register now here
experiencing? The **Virtual Support Groups** are for you!

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](https://www.knowaml.com/en/get-involved/world-awareness-day). **Together, we are strong!**

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**Spotlight Clinical Trial**

**RECRUITING**

**Relapsed/Refractory Severe Aplastic Anemia**

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).

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**Spotlight Clinical Trial**

**Recruiting**

**PNH Patients with Clinically Evident Extravascular Hemolysis**

The purpose of this study is to evaluate the efficacy of danicopan as add-on therapy to a complement component 5 (C5) inhibitor (eculizumab or ravulizumab) in participants with PNH who have clinically evident EVH.

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**Get involved!**

Find out how with our partners at #KnowAML here: [https://www.knowaml.com/en/get-involved/world-awareness-day](https://www.knowaml.com/en/get-involved/world-awareness-day)
Don't forget to care for your emotional health, both during and after treatment. Find out more here: [https://www.aamds.org/treatments/self-care/six-areas/emotional-health](https://www.aamds.org/treatments/self-care/six-areas/emotional-health)

**MDS Update**

Here's the latest selected for you:

**Treating Options for MDS/AML Patients Who Cannot Tolerate Standard Chemotherapy:** A recent clinical trial (NCT03404193) looked at the benefits for patients by adding Venetoclax (VENCLEXTA) to decitabine as a treatment option for patients with higher-risk MDS and newly diagnosed AML. The study has found that the combination is well tolerated and can help control abnormal cells enough to prepare patients for transplant. There are some side effects which you should discuss with your treating hematologist/oncologist.
You can read about this study and others in our ASCO EHA 2020 Research Summaries: MDS/AML here:
https://www.aamds.org/education/patient-guides-and-fact-sheets

**ASH 2020: MDS Updates:** We've scheduled a second webinar for MDS patients to review important findings from the December 2020 ASH meeting with Dr. Hetty Carraway, Cleveland Clinic. You are invited to submit your questions in advance to help@aamds.org or during the live webinar on May 20, 2021. Registration is now open: ASH 2020: MDS Updates: We've scheduled a second webinar for MDS patients to go over all of the important findings from the December 2020 ASH meeting with Dr. Hetty Carraway, Cleveland Clinic. You are invited to submit your questions ahead of time to help@aamds.org or during the live webinar on May 20, 2021. Registration is now open:
https://www.aamds.org/webinar/ash-2020-mds-updates

New **MDS Clinical Trial** for Adult **Higher-Risk MDS Patients** who are RARA-positive: This study compares a new drug called SY-1425 in combination with azacitidine to azacitidine alone. Participants will need to provide a blood sample. For more information, please click here:
https://www.aamds.org/treatments/clinical-trials/randomized-double-blind-placebo-controlled-phase-3-study-sy-1425-plus

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Aplastic Anemia and MDS International Foundation
4330 East West Highway Ste 230 | Bethesda, Maryland 20814
3012797202 | help@aamds.org

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