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Foundation Update

April 2021

In this issue: Thank you to **Volunteers** | **June** Conference | **Webinars** plus One! | Surprising **SAA Patient Story** | **THANK YOU** to March for Marrow Sponsors | March for Marrow CA | MORE **Support Groups** | Clinical Trials | Mental Health Month | **AML World** Awareness Day | **MDS Update** |



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



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



Dr. Mikkael Sekeres

Webinar

**Establishing Goals
of Therapy
While Managing MDS**





Dr. Hetty Carraway

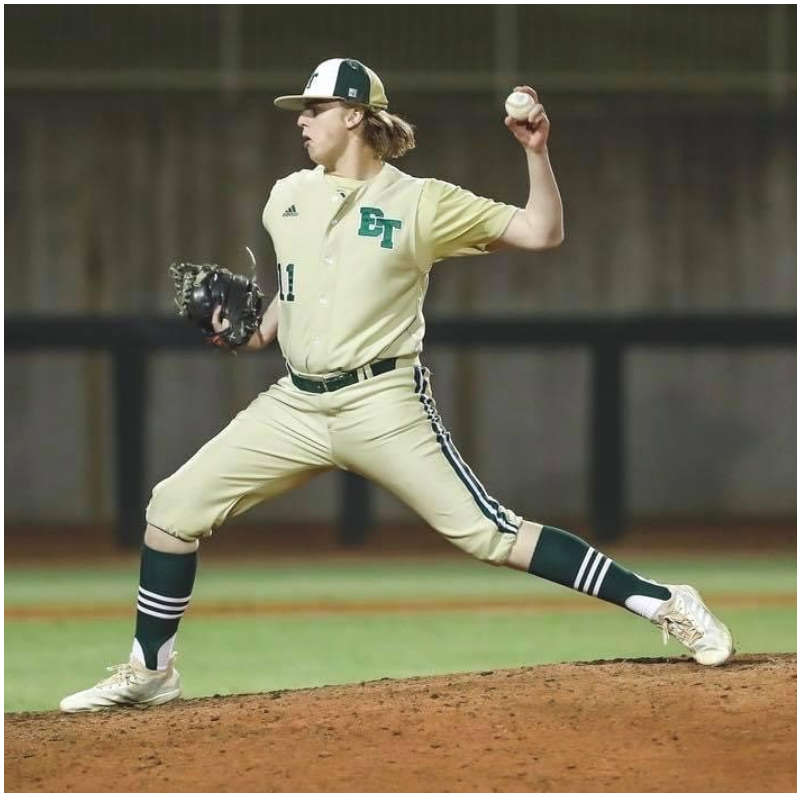
Join expert clinicians, a patient advocate, and a patient for “Establishing Goals of Therapy While Managing Myelodysplastic Syndromes,” an interactive discussion of MDS and potential treatment approaches.

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!



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Help make this event special -- [Sign up](#) to participate in the Virtual March for Marrow California, 5K Run and Patient and Family Walk!

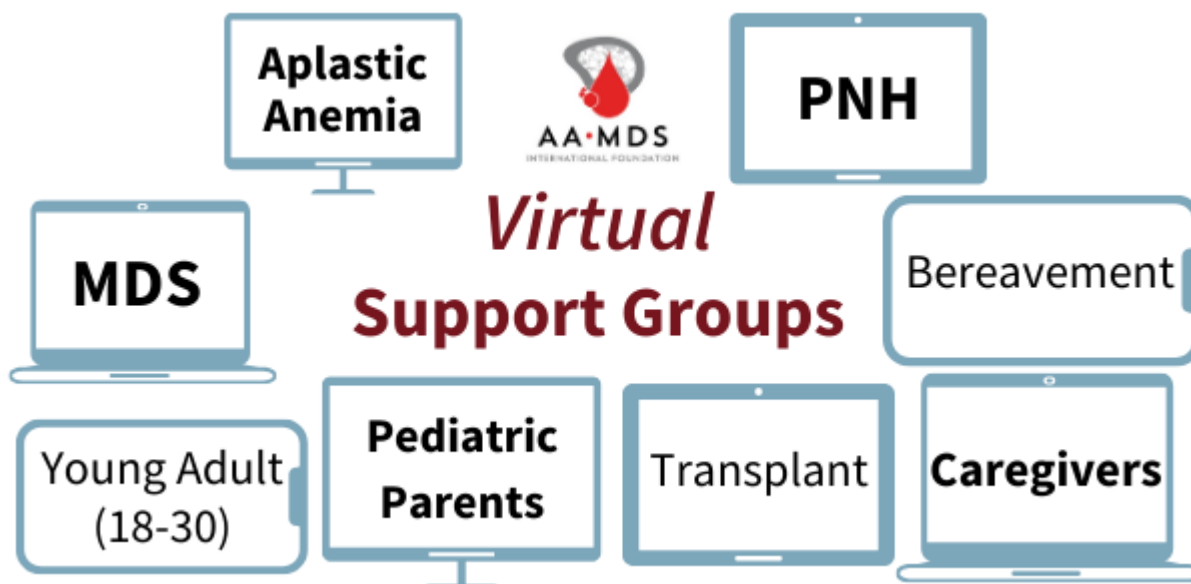
Gather your friends and family to walk as a team; **everyone is welcome** to participate in the virtual event.

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

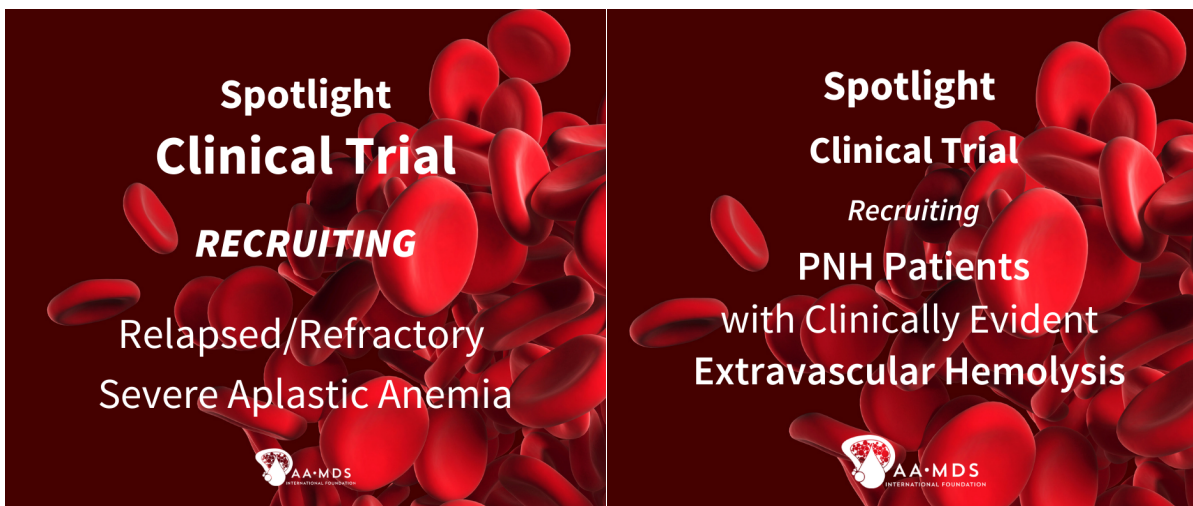
[Register now here](#)



Are you looking for others who are dealing with the same issues that you're

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](#). **Together, we are strong!**



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).

[Learn More](#)

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.

[Learn More](#)

Get involved!

Find out how with our partners at #KnowAML here: <https://www.know-aml.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>



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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