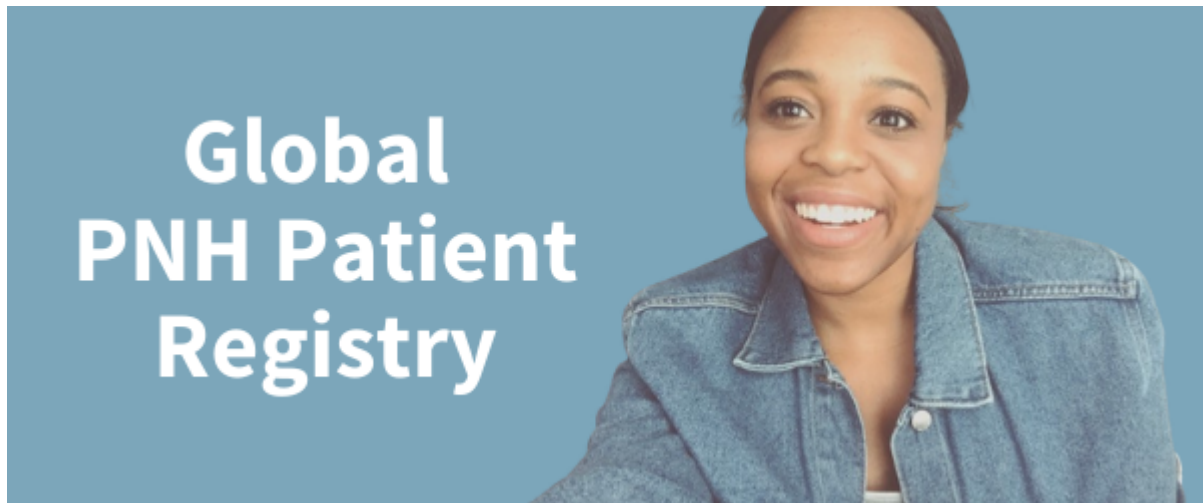




Foundation Update

May 2021

In this issue: **Global PNH Patient Registry** Opens | Patient and Family Summer Virtual **Conference** | Webinars | **On-Demand** MDS Webinar | Hailey's **Story** | Thanks to Sponsors | **Support** Groups | **MDS** Clinical Trial | **Military Appreciation** Month | **MDS Update** with Virtual **Conference** from Seattle, WA



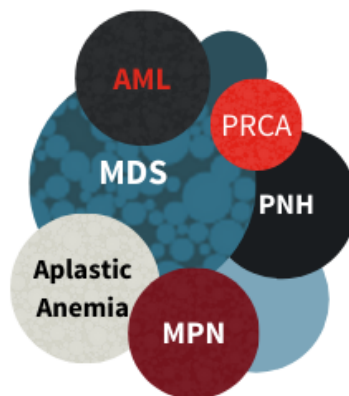
Have you been wondering how to **get involved** with PNH research but did not know where to start? Here's your chance! **Check out** the Global PNH Patient Registry at pnh.iamrare.org



Summer Global

Patient & Family Conference

July 16 & 17, 2021



Registration is open for this **VIRTUAL** conference, and you're invited! Learn the latest news and research into your condition, and how to deal with it!

Use the link below and mark your calendar today!

Information and Registration for the Summer Virtual Conference



Upcoming Webinars

Here are the next All-New Webinars for you!

All Times EDT-US

- **ASH 2020: MDS Updates** Thursday, May 20, 2021 at 12:00pm (EDT)

- June Webinars will focus on Patient Panels. Find them here: <https://www.aamds.org/education/webinars>



Recording Now Available!

Establishing Goals of Therapy While Managing MDS



Dr. Mikkael Sekeres

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.

Watch the recording [here!](#)

"Pack your Bags and Head to the Hospital"

Hailey's Story of Hope



"Ask questions and be an advocate for your child."

10 years after treatment, Hailey's mom has perspective and advice for pediatric parents. Read their story [HERE](#), where you can also find out about Christy's book about the family's experience, [Pink Elephants](#).

Thank You!



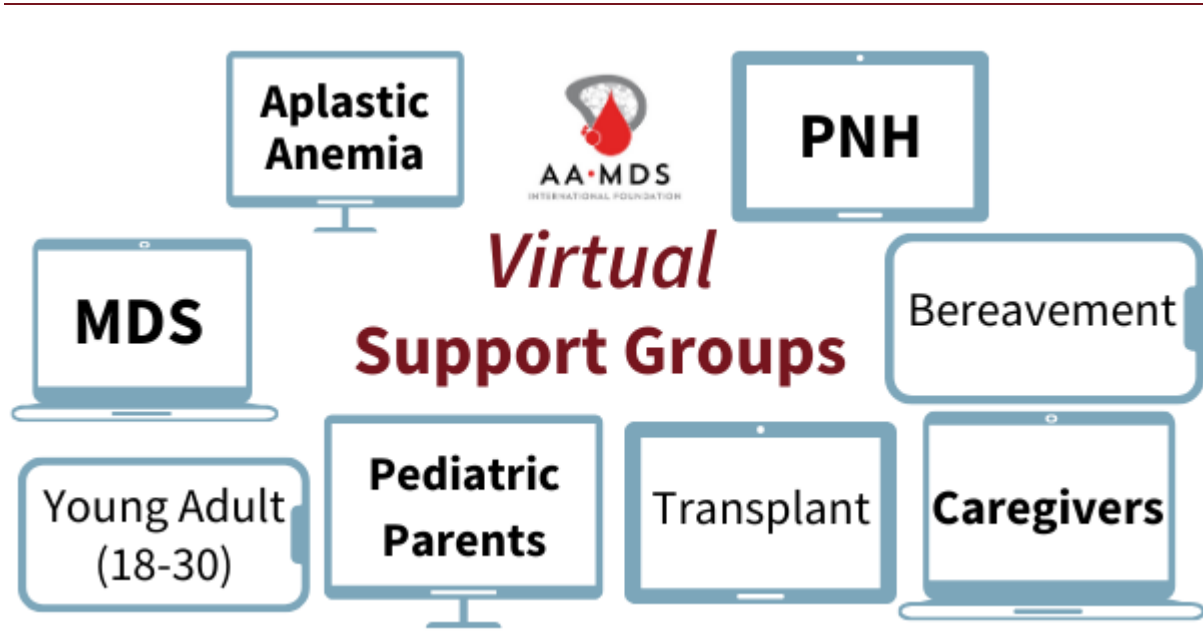
Gold Sponsor



Silver Sponsor



Bronze Sponsor



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!**



(Verona) A Randomized, Double-Blind, Phase 3 Study Evaluating the Safety and Efficacy of Venetoclax in Combination with Azacitidine in Patients Newly Diagnosed with Higher-Risk Myelodysplastic Syndromes (Higher-Risk MDS)

Please follow this link for more information to share with your specialist: <https://www.aamds.org/treatments/clinical-trials/verona-randomized-double-blind-phase-3-study-evaluating-safety>

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.



May is Military Appreciation Month!

We know that many veterans will be diagnosed with bone marrow failure diseases. Veterans, please check out our group just for you on Facebook here: <https://www.facebook.com/groups/366042994184734>

MDS Update

Here's the latest selected for you:



Aplastic Anemia, Myelodysplastic Syndromes, and Myeloproliferative Neoplasms:

The 8th Seattle (Virtual) Patient Conference

Saturday, June 26, 2021

with educational sessions on aplastic anemia, MDS, PNH and MPNs

Dr. H. Joachim Deeg has assembled an all-star faculty for this biennial conference with sessions on aplastic anemia, PNH, MDS, MPNs, and more. This free conference will be held via Zoom and can be joined by video or telephone.

Register Today!

COVID-19 Guidance for MDS and other bone marrow failure patients on vaccinations: If you missed the webinar or our latest guidance on vaccinations, you can find out more on our COVID-19 page:

<https://www.aamds.org/education/covid-19>

AAMDSIF has the latest updates on MDS research available for digital download (or we can send you a copy by mail). Download the **ASH 2020: MDS and Bone Marrow Failure Disease Research Summaries** here:

<https://www.aamds.org/education/patient-guides-and-fact-sheets>

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



Follow Us



Aplastic Anemia and MDS International Foundation

4330 East West Highway Ste 230 | Bethesda, Maryland 20814

3012797202 | help@aamds.org

Having trouble viewing this email? [View it in your web browser](#)

[Unsubscribe](#) or [Manage](#)
[Your Preferences](#)