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Foundation Update

June 2021

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**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

You're invited!

Sessions have been designed for patients, family members and caregivers who are affected by bone marrow failure disease including aplastic anemia, PNH, MDS, MPNs, and other bone marrow failure diseases.

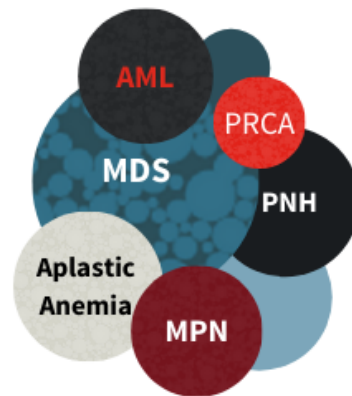
Register for Conference on June 26th



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!

Information and Registration for the Summer Virtual Conference

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

Research in the News

NEW FDA APPROVALS!

- U.S. Food and Drug Administration (FDA) has approved Empaveli (pegcetacoplan) injection to treat **adults with paroxysmal nocturnal hemoglobinuria (PNH)**, a rare, life-threatening blood disease. Empaveli is the first PNH treatment that binds to complement protein C3. Read about it [here](#).
- U.S. Food and Drug Administration (FDA) has **approved the expanded use** of ULTOMIRIS® (ravulizumab-cwvz) **to include children** (one month of age and older) **and adolescents with paroxysmal nocturnal hemoglobinuria (PNH)**. ULTOMIRIS® , a long-acting C5 inhibitor, is now the first and only FDA-approved medicine for children and adolescents with PNH. Read about it [here](#).

Father's Day June 20th



How are you honoring your Father on Sunday? Make a donation today to keep providing Dads with the answers, support, and hope they need.

Make your gift in honor or in memory of your father or someone you admire!

I'm giving for
Father's Day

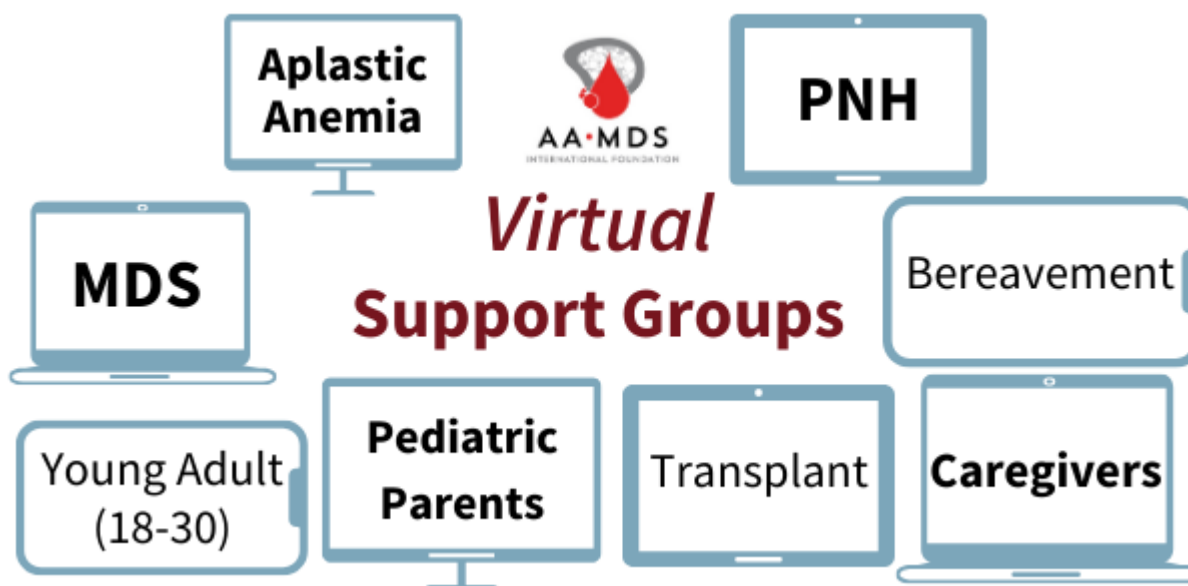
Upcoming Webinars



Here are the next All-New Webinars for you!

All Times EDT-US

- Wed, 06/23/2021 [Living with Aplastic Anemia: a Patient Panel Discussion](#)
- 2:00pm (EDT)
- Thu, 06/24/2021 - [Advancing Research Through the Global PNH Patient Registry: Q & A with Dr. David J. Araten](#)
3:00pm (EDT)
- Mon, 06/28/2021 - [Living with PNH: A Patient Panel Discussion](#)
2:00pm (EDT)
- Wed, 06/30/2021 [Living with MDS: A Patient Panel Discussion](#)
- 2:00pm (EDT)
- Thu, 07/08/2021 - [Living with GVHD: A Transplant Patient Panel Discussion](#)
2:00pm (EDT)
- Thu, 08/05/2021 - [Living with a Pediatric Bone Marrow Failure Disease: a Parent Panel Discussion](#)
2:00pm (EDT)



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!**



A phase I/II Study of REGN7257 (Anti-interleukin 2 receptor subunit gamma [IL2RG] monoclonal antibody) in patients with severe aplastic anemia that is refractory to or relapsed on immunosuppressive therapy. Please click [HERE](#) for more information.

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

Webinar
Recording
**ASH2020:
MDS Updates**



Hetty Carraway, MD



Dr. Carraway does a deep dive into the **most promising** MDS treatments and research presented at the December 2020 ASH meeting including drugs that are in the development pipeline and will **soon be available** for patients.

Watch on-demand here: <https://www.aamds.org/webinar/ash-2020-mds-updates>

Living with

MDS

Panel
Discussion



Be sure to register and attend on 6/30/21 at 2pm EDT.

Register

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!

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