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FOUNDATION Update

Connecting Patients and Families with News and Expert Opinion



2019 Patient & Family Conference with Special Kids Program

Saturday, July 20, 2019, Milwaukee, Wisconsin

You are invited to join us for our FREE 2019 Patient & Family Conference in beautiful Milwaukee, Wisconsin on Saturday, July 20th. This conference includes special programming for pediatric patients, families, and caregivers led by faculty members Dr. David Margolis, MD (Children's Hospital of Wisconsin) and Dr. Inga Hofmann-Zhang, MD (American Family Children's Hospital). We will also offer our [full program](#) of adult education for patients, families, and caregivers. To register online, [click here](#).



AAMDSIF Offers Conference Sessions Via Facebook Live!

We launched our first Facebook Live at our Albuquerque Patient & Family Conference earlier this year and thousands of patients, families, caregivers, and health professionals have joined our conferences virtually. If your schedule doesn't permit traveling to Milwaukee in July, you can still join us from your mobile phone, desktop computer or tablet. Just RSVP that you're "GOING" to the [Milwaukee Conference on Facebook](#) and we'll post details the week before. Questions? Give us a call at (301) 279-7202 x 127 for Julie Powers, Senior Director of Patient Advocacy and our official videographer.

Free Webinars



Check Out Our New Webinars!

Chosen by patients, presented by leading experts

Not only are our webinars available 24/7 on-demand but we have added more than a dozen new subjects on topics selected by our patients. We have more than [200 webinars](#) available for immediate viewing and we are adding several new webinars each month. Your free AAMDSIF webinar account gives you access to our entire catalog for viewing on your mobile phone, tablet or computer.

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March for Marrow Registration Now Open! Detroit, NYC and DC Dates Announced

It's time to get out there and walk or run in one of our many events across the nation to support the Foundation's work to find a cure. You can join in person or you can be a VIRTUAL racer by signing up online. For more information about our events, please check out the [website](#) and click on the event below for registration and more.

Sunday, September 8, 2019: Detroit

[Tartan Trailblazers March for Marrow](#)

Sunday, September 15, 2019: New York City

[March for March Walk for PNH](#)

Saturday, September 28, 2019: Washington DC

[March for Marrow](#)



[ASH 2018 MDS & AML and Aplastic Anemia & PNH Research Summaries Now Available](#)

Patients are now able to download the latest in medical research on Aplastic Anemia, PNH, MDS and AML from our website. All you need to do to download the Research Summaries is to provide your name and email address. We highly recommend downloading these documents for all patients and health professionals!

MDS Update: Going Digital

Meeting the needs of patients across the globe.

AAMDSIF will be moving our quarterly MDS Update publication to a digital platform by the end of 2019. If you or someone you know would like to receive a copy of this publication, please let us know by signing up [online](#) or by calling (800) 747-2820. If you are currently a digital subscriber, you will continue to receive it via email.



[AAMDSIF 35th Anniversary Awards Luncheon Celebration](#)

We had a wonderful event celebrating the many visionary leaders, dedicated volunteers and generous supporters of the Aplastic Anemia & MDS International Foundation. We are humbled by the compassion and energy that our community of patients, family members, caregivers and health professionals devote to finding answers, providing support and giving hope for these rare blood cancers and bone marrow failure diseases. We put together a [video](#) of

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the event for you to enjoy!

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Clinical Trial - Recruiting Participants

Optimizing Haploidentical Aplastic Anemia Transplantation (CHAMP)

Acquired SAA is a rare bone marrow failure disorder with an estimated annual incidence of two cases per million and with over 600 new cases in the United States each year. A major challenge in treating acquired SAA is the management of patients who are refractory to immunosuppressant therapy (IST) or have relapsed after IST. HSCT is the only curative option for these patients but many are ineligible because they lack a suitable donor. The Blood and Marrow Transplant Clinical Trials Network (BMT CTN) seeks to increase options for these patients by using novel therapeutic strategies of GVHD prophylaxis with PTCy to expand the donor pool to include haploidentical donors. The goal of this protocol is to test whether optimized approaches using haploidentical donors will achieve acceptable outcomes in SAA patients.

For more information, please click [click here](#) or contact Dr. Amy DeZern at adezern1@jhmi.edu



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