

February 2019



AAMDSIF Launches New and Improved Website for You!

For the last 35 years, AAMDSIF has served patients, families, and caregivers with print publications, our patient helpline, conferences, research grants, and our [website](#). Today, we are pleased and proud to announce that we have made some really significant updates and improvements to our website so that your experience is much better!

What's New?

- **Great for All Devices:** With almost 2/3 of our visitors using a smartphone or tablet, the new website was designed with smaller screens in mind but it still works (and looks) great on a desktop or laptop computer.
- **Easily Find What You're Looking For:** There's a search box at the top of each page so you can find what you need quickly and easily.
- **New Translation Options:** Our international patients, families, caregivers, and health professionals can now read our website in one of the 30+ languages available through our translation function.
- **How We Can Help:** We've added a simple

sidebar to many pages so that patients, families, caregivers and health professionals can easily access what they need, from the link to order educational materials to talk to one of our Peer Support Counselors.

We couldn't have made these improvements without the guidance and support of a dedicated team of volunteers who spent countless hours advising staff and testing the new site. Thanks to Neil Cuadra, Stephanie Dillon Hamm, Stephen King, Judy Paulette, Melanie Marquez, and our staff and to you, our patients, our families, our caregivers, and our health professionals. Explore the new site and you might even see yourself in one of our many photographs!

Warm regards,



CEO and Executive Director



We Want to Hear from You!

Every few years, we invite our patients, families, caregivers, health professionals, and other stakeholders to share their thoughts about the programs and services offered by AAMDSIF. We want (and need) to hear from you. The short [online survey](#) can be done anonymously and takes just a few minutes.

Your input helps us plan better Patient and Family Conferences, offer different webinar topics, helps us advise health care professionals and talk to stakeholders and funders about what you need and want.

Please take just a few minutes today to take our [survey](#). We appreciate you!

March 30, 2019 (8am - NOON)
AAMDSIF Patient and Family Conference



Albuquerque, New Mexico

We are thrilled to be taking the first [AAMSDIF Patient and Family Conference](#) of 2019 to beautiful Albuquerque, New Mexico. There is no charge to attend the Conference but pre-registration is required. The Conference is hosted in partnership with the University of New Mexico Cancer Center and is presented with support from Celgene, Jazz Pharmaceuticals and Apellis Pharmaceuticals.

New This Year: AAMDSIF is pleased to bring you Dr. Rafael Bejar of the University of San Diego's presentation on MDS via Facebook Live! Simply RSVP for the Conference and you'll receive a reminder to join us for the LIVE presentation at 9am MT via Facebook Live! The presentation will also be uploaded to the AAMDSIF [YouTube Channel](#) for later viewing.



Facts for Life

Be A Marrow Donor on National Donor Day – Or Any Day!

Have you or someone you know had a bone marrow/stem cell transplant or received a blood transfusion? Then you know how important those donations were to you and your loved one. February 14th is Valentine's Day, but did you know it's also National Donor Day? This Valentine's Day, honor your loved one by joining the Be [The Match Registry](#), donating blood, or organizing a drive. It's easy, painless and a great way to show the spirit of the day.



AAMDSIF Online Academy: Free Webinars

Are you looking for more information from the top experts on aplastic anemia, MDS, PNH or related diseases? All webinars are free -- view our currently

[archived webinars](#). We have more than 200 for you to choose from and we are adding more every month. You can also suggest webinar topics by taking our [2019 Patient Survey](#).



Start a Community Connections Support Group in Your Community

[Community Connections](#) are volunteer-led local support groups that provide support and encouragement to patients and families affected by bone marrow failure diseases. Each support group looks slightly different since it's up to its members to decide how they want their group to function. Some groups meet monthly, some meet every other month or even quarterly. These groups provide a safe place for patients and families to share experiences, learn from each other and get support on their journey. If you are interested in connecting with a support group in your area or starting a group, please contact us, help@aamds.org or 800-747-2820 x140.



Jane Biehl: Living With Fatigue

"A standard dictionary definition of fatigue, according to Medicine, is, 'extreme tiredness resulting from mental or physical exertion or illness.' Fatigue can also be acute and come on suddenly or be chronic and persistent. This describes what many of us experience."

MDS patient Jane Biehl began writing about her experiences and views on life as a MDS patient and survivor. In just over two years, she's written over 50 articles. Many of these have been published in [Cure magazine](#) and she's adding new ones all the time. This month, we present [Jane's article](#) on experiencing and living with cancer fatigue.

Houston March for Marrow in Enters 10th Year!

[Join us](#) for the 10th Annual March for Marrow Houston on March 30th! [Register today](#) to help organizers,



patients, families and friends raise awareness. Can't make it to Northshore Park? Everyone is welcome to walk virtually. Grab some friends and go for a walk in your favorite park or neighborhood.

Have you ever considered hosting an event to help raise awareness? We can help you make it a reality! Email ambassadors@aamds.org to find out how we can help.

Interested in organizing an event or just want to help?

Contact Margaret at fitzgerald@aamds.org.

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Marrowforums



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