



Meet Me in St. Louis for World MDS Awareness?

AAMDSIF Bone Marrow Failure Disease Patient & Family Conference in St. Louis, MO on Saturday, October 26, 2019 ([In-Person](#) or Via [Facebook Live](#))



AAMDSIF is delighted to host our next Patient & Family Conference in St. Louis, Missouri on Saturday, October 26, 2019 from 7:30am - 12:30pm in partnership with the faculty and staff of Washington University in St. Louis School of Medicine and with faculty from the newly launched Global Pediatric MDS Initiative. We are honored to have [Matthew Walter, MD](#) as our Faculty Director. Dr. Walter is the newly appointed head of the the [Edward P. Evans Center for Myelodysplastic Syndromes](#) which is supported through a \$5 million grant from the [Edward P. Evans Foundation](#).

The [Patient & Family Conference](#) is **FREE** to attend and includes sessions on:

- The Latest in Aplastic Anemia: Managing Your Disease and New Research
- Living with MDS: Understanding Your Treatment Options
- What is CLL? Overlap and Impact for Bone Marrow Failure Disease Patients
- Pediatric Bone Marrow Failure Diseases
- The Latest in PNH: New Treatment Options and Dealing with Side Effects
- AML: What and If a Transplant is an Option
- Mindfulness and Bone Marrow Failure Diseases
- Bone Issues and Bone Marrow Failure Diseases

AAMDSIF events are open to patients, their families, loved ones, friends and caregivers as well as local health professionals. We'll provide a tasty breakfast with vegetarian and gluten-free options. Please let us know about your dietary restrictions on your registration form.

If you have questions about the Conference or would like help with registration, please call us at (800) 747-2820 or send an email to help@aamds.org.

In Person Registration:

<https://aamdsif.salsalabs.org/2019stlouis/index.html>

Facebook Live Registration:

<https://www.facebook.com/events/473389443513520/>



The Aplastic Anemia & MDS International Foundation Announces 2019 Research Grants

AAMDSIF Invests in Life-Changing Research

For 30 years, AAMDSIF has provided research grants totaling over \$5 million to an international group of more than 90 researchers to help advance the understanding and treatment of aplastic anemia, myelodysplastic syndromes (MDS), and paroxysmal nocturnal hemoglobinuria (PNH). These two-year grants have contributed to new insights into the causes and therapeutic approaches for these diseases.

For more information about the research grants made to [Elissa Furutani, MD](#) and [Christin DeStefano, MD](#) and all of the other research grants made by AAMDSIF over the last three decades.



New Clinical Trial Opportunity for MDS Patients

Geron IMerge Clinical Trial enrollment is now open!

[IMerge](#) is a two-part Phase 2/3 clinical trial of Imetelstat (GRN163L) in transfusion dependent patients with lower risk MDS who are relapsed after or refractory to erythroid stimulating agents (ESAs). The Phase 3 portion is planned to enroll approximately 170 patients in a randomized (2:1 ratio of imetelstat: placebo), double-blind, placebo-controlled clinical trial to test the hypothesis that imetelstat improves the rate of red blood cell transfusion independence (TI). The trial is planned to be conducted at multiple medical centers globally, including North America, Europe, Middle East and Asia.

To learn more about the trial or to contact the trial sponsor, click [here](#).

Free Webinars



We've Added New Webinars on Biosimilars, the Complement System and MDS in Older Adults!

Webinars available LIVE and on-demand!

- [10/24/19](#): "Treating MDS in Older Adults" with [Dr. Catherine Lai from MedStar Georgetown University Hospital's Lombardi Comprehensive Cancer Center](#) (2:30pm ET)
- [11/05/19](#): "Patients Journey to Transplant" with [Costa Herbert, RN from Fred Hutchinson Cancer](#)

October 2019 AAMDSIF Update

[Research Center](#) (4pm ET)

- [11/06/19](#): "Complement System and PNH" with [Dr. Bart Scott of the Seattle Comprehensive Cancer Care Alliance](#)/University of Washington Medical Center/Fred Hutchinson Cancer Research Center (3pm ET)
- [11/08/19](#): "Pediatric BMT" with [Dr. Michael Pulsipher from the Children's Hospital of Los Angeles](#) (1pm ET)
- [11/13/19](#): "Biosimilars: Impact for Patients" with Cate Lockhart, Executive Director at [Biologics and Biosimilars Collective Intelligence Consortium](#) (1pm ET)

AAMDSIF webinars are available on-demand, 24/7 with your free AAMDSIF account. [Sign up today](#) and see what we have to offer! <https://www.pathlms.com/aamdsif>



World MDS Awareness Day: AAMDSIF in Italy!

Supporting Patients Around the World

In observance of World MDS Awareness Day, AAMDSIF will be participating in two educational programs in Florence, Italy:

- A Patient Forum in collaboration with the [Associazione Italiana Pazienti con Sindrome Mielodisplastica](#)
- A professional education program in collaboration with the [Fondazione Italiana Sindromi Mielodisplastiche](#)

AAMDSIF Medical Advisory Board member [Dr. Valeria Santini of the University of Florence](#) helped to organize and will be speaking at both of these meetings, and Dr. Neal Young, also an AAMDSIF Medical Advisory Board member, will be presenting at both meetings. In preparation for these meetings, the AAMDSIF patient guides for MDS and AML were translated into Italian by AAMDSIF Board member Stephanie Hamm and her husband Bill and they will soon be available on the AAMDSIF website with our other patient education materials in English, Spanish, French, German and Portuguese.



AAMDSIF: Investing in Research

Dr. Alina Dulau-Florea is a staff hematopathologist at the NIH Clinical Center in Bethesda, MD. She reports that because of her 2016 AAMDSIF research grant,

"I was invited to present our research data at two international conferences and to attend the AAMDSIF Scientific Symposium, which were great opportunities to connect with the scientific community working in the field of bone marrow failure and to learn of patients forums and experiences. All these events enriched my work and life experience. The AAMDSIF funds raised by patients, families

and communities gave me the great opportunity to work in a field that I am truly interested in, that of bone marrow failure, including aplastic anemia, MDS and PNH. I feel very fortunate to be able to study a rare but debilitating disease, with the aid of AAMDSIF and the patients who are enrolled on protocols at the NIH and who provide blood and bone marrow samples for clinical and research studies. It was a great honor and pride for me to present our data at national and international conferences, and interact with other scientists studying the same diseases, with whom I shared our valuable experience. I wish I had the chance to express my gratitude to the AAMDSIF members, the patients and their families for their invaluable support."

Dr. Dulau-Florea was awarded a grant in 2016 to analyze normal and abnormal cells in patients with PNH. To learn more about this research, there is a summary available on our [website](#).

If you would like to learn more about becoming a partner in funding research through AAMDSIF, please contact Julie Lowe at lowe@aamds.org or by calling (301) 279-7202 ext. 103



AAMDSIF: Helping Patients Succeed

Meet Sarah Nesheim, Aplastic Anemia and PNH Patient, Survivor and Community Inspiration!

Sarah was diagnosed in 2014 with Aplastic Anemia and PNH and she's sharing her story in the hopes that we can work together to find a cure for herself and others!

"When I was diagnosed, I had several questions -- why did this happen to me, and why now?"

Her diagnosis forced her to dig deep and find the strength that many people never need to discover. Through her journey she realized that some friends and significant others fall away and it's made her so grateful for those who are a true presence in her life.

"Having a chronic illness changes relationships, for better or for worse."

Since her diagnosis, Sarah has become an advocate and inspiration for patients, families and caregivers by attending AAMDSIF [Patient & Family Conferences](#), joining the [Patient Education Council](#), serving on the PNH Committee, sharing her story on the AAMDSIF [podcast](#) and planning a local event to raise awareness. You can read Sarah's full story [here](#).

[Donate today](#) to help patients receive the education and resources needed to understand their diseases, treatments and make important connections to share experiences.



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