March for Marrow: Washington DC

*Join in person or virtually to help us find a cure!*

The last walk of our September series is coming up on Saturday, September 28, 2019. Our volunteers and staff will be on hand to walk (or run) with you in person or online. Sign up today to make a difference in the lives of so many who are waiting for a cure.

**Saturday, September 28, 2019: Washington DC**

[National March for Marrow](https://www.eventbrite.com/e/march-for-marrow-5k-registration-62955435402?aff=aamds)

This walk is generously sponsored by patients, families, caregivers, friends, communities and our charitable partners including:

**DC Champions**
THIS SATURDAY! AAMDSIF is going to be LIVE in Pittsburgh at our Patient & Family Conference (In-Person or Via Facebook Live)

It's not too late to attend our FREE Patient & Family Conference this Saturday, just outside of Pittsburgh! Can't make it in person? You can watch sessions on Myelodysplastic Syndromes (MDS) and Acute Myeloid Leukemia (AML) with Salman Fazal, MD with the Allegheny Health Network.

In Person Registration:

Facebook Live Registration:
https://www.facebook.com/events/2385256058228607/
New Clinical Trial Opportunity for Higher Risk MDS Patients: PACTN

**Personalized Adoptive Cellular Therapy Targeting MDS Stem Cell Neoantigens (PACTN)**

This is a Phase 1 open label, dose escalation clinical trial of Personalized, Adoptive immunotherapy by Cytotoxic T cells that are targeted to patient-specific cancer cell Neoantigens (PACTN) for some higher risk MDS patients. It's primary goal is to learn the safety and tolerability of PACTN infusion and secondarily, if PACTN show signs of being effective. For more information about the trial, please see the AAMDSIF [website](https://aamdsif.org). You can also contact the clinical trial coordinator directly: Kimberly Aguilar at the University of California San Diego via email at k1aguilar@ucsd.edu or by calling (858) 534-5201.

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**New Webinars including the latest in MDS and AML research, the History of Aplastic Anemia and the Bone Marrow Transplant Patient’s Journey!**

*Webinars available LIVE and on-demand at your convenience.*

- **9/24/19**: "2019 Research Updates on MDS and AML from EHA and ASCO” with [Dr. Gail Roboz from Weill Cornell](https://weillcornell.org) (11am ET)
- **9/26/19**: "History of MDS - Past, Present and Future” with [Dr. Pamela Becker from Seattle Cancer Care Alliance](https://seattlecancer.org) (1pm ET)
- **9/30/19**: "Refractory/Relapsed AML in Children” with [Dr. Michael Burke from Children's Hospital of Wisconsin](https://chop.edu) (3pm ET)
- **10/07/19**: "History of Aplastic Anemia - Past, Present and Future” with [Dr. Phillip Scheinberg with Hospital Sao Jose, Beneficencia Portuguesa de Sao Paolo in Brazil](https://hospital-sao-jose.com) (5pm ET)
- **10/18/19**: "CLL and Transplant - Get the Facts” with [Dr. Daniel Weisdorf from University of Minnesota Clinical and Translational Science Institute](https://medicine.umn.edu) (3pm ET)
- **10/24/19**: "Treating MDS in Older Adults” with [Dr. Catherine Lai from MedStar Georgetown University Hospital's Lombardi Comprehensive Cancer Center](https://medstar.org) (2:30pm ET)
- **11/05/19**: "Patients Journey to Transplant” with [Costa Herbert, RN from Fred Hutchinson Cancer Research Center](https://fredhutch.org) (4pm ET)
- **11/06/19**: "Complement System and PNH” with [Dr. Bart Scott of the Seattle Comprehensive Cancer Care Alliance](https://seattlecancer.org) /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](https://chla.org) (1pm ET)
BLOOD CANCER AWARENESS MONTH
This month, AAMDSIF has joined together with dozens of other advocacy organizations to help patients, families, caregivers and communities understand the impact that blood cancers can have on the lives of so many. Our packed September schedule of webinars, conferences, walks, runs and support group meetings is in honor of our patients. Please consider making a donation in support of someone you love with blood cancer.

NEW SEASON: AAMDSIF Podcast for Patients
Bringing you answers, support and hope!

Don’t miss the newest episodes of our Podcast for Patients series for our patients, families, caregivers and friends.

Persistence, Advocacy, and a Clinical Trial: Theresa is now a Survivor!
Meet Theresa Elgin, Aplastic Anemia and PNH survivor who shares her story of how persistence, self-advocacy and a clinical trial made all the difference in her life. She’s got a busy life these days working full-time, caring for her family and volunteering for the Foundation.

Hedgehog Pathway Inhibitors, Vitamin C, and MDS: what you need to know, featuring Dr. Raoul Tibes of Perlmutter Cancer Center at NYU Langone.

We are so happy to have Dr. Raoul Tibes on the show to talk about MDS treatment options including hedgehog pathway inhibitors. (You’ll have to listen to hear about the hedgehog!)

Our next episode (coming soon!) features Dr. Corey Cutler who explains the ins and outs of Stem Cell Transplant! You can listen on the AAMDSIF website or through Google Play and the iTunes store.

AAMDSIF: Investing in Research
AAMDSIF offers a number of opportunities for patients, families and communities to invest in critical research for diseases like Aplastic Anemia, MDS and PNH.

This year AAMDSIF is observing the 30th Anniversary of our Research Grants program, which has provided over $5 million to 92 researchers since it began in 1989. One of these grantees is Lukasz Pawel Gondek, M.D., Ph.D., Assistant Professor of Oncology, Johns Hopkins University.
Dr. Gondek received a research grant from AAMDSIF in 2006 to study the genomics of MDS.

“It was my very first successful grant application and it not only launched my career but also helped create a new avenue for genomic research in my mentor’s lab. The preliminary data we generated helped us secure subsequent funding from NIH and other sources.”

Dr. Gondek’s mentor at Cleveland Clinic was Dr. Jaroslaw Maciejewski, a past AAMDSIF grantee himself and a longtime member of our Medical Advisory Board, not to mention an internationally recognized expert in bone marrow failure disease. Dr. Gondek continues to study the genetic and molecular underpinnings of MDS in his own lab at Johns Hopkins.

“Through the years, AAMDSIF has been a tremendous support for young investigators who are now changing the face of the bone marrow failure research,” Dr. Gondek noted. “It seems to be a pattern that the early investigators funded by AAMDSIF become the successful independent scientists. Some of the key investigators in the field of bone marrow failure are the former AAMDSIF grantees. The benefit of the award is twofold: the financial support that helps generating an important new data and connection to the field. I hope that with a tremendous help and support from patients and their families this mission will continue.”

Learn more about the impact of AAMDSIF support for Dr. Gondek’s research in this interview:
https://www.youtube.com/watch?v=pceG4k4bBxo&t=262s

His mentor, Dr. Jaroslaw Maciejewski, also spoke about the significance of AAMDSIF grant support to his career:
https://www.youtube.com/watch?v=ebMnWQnweJE&t=2s

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