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Registration is OPEN for this All-Virtual Patient & Family Conference! Listen to internationally known experts in your disease, find your peers, and listen to these key speakers:

Connie Britton, an Emmy and Golden Globe nominated actress and AAMDSIF advocate
Representative Doris Okada Matsui represents California's 6th congressional district. She is a long-time friend of AAMDSIF.

David C. Fajgenbaum is an American immunologist assistant professor at the Perelman School of Medicine of the University of Pennsylvania. He is most well known for his research into Castleman disease and his book, Chasing My Cure: A Doctor’s Race to Turn Hope Into Action.

And many thanks to American Pianist, George Winston, for providing the music for the conference.
YOU can make a difference to bone marrow failure patients and their families in your community and beyond by registering to March for Marrow and building a virtual fundraising team!

We need your help now, more than ever, to spread awareness and raise funds to help this special community. Without you, we can't meet the goal to deliver patient services in 2020. Will you help?

For Health Professionals:

Seventh International
Bone Marrow Failure Disease Scientific Symposium

July 15, 16 & 17

Join us for this exciting, virtual International Bone Marrow Failure Disease Symposium! Each session includes presentations by an international faculty of experts followed by open discussion. Speakers will address the most up-to-date research and issues in each topic area. Click HERE for more information; Register HERE for this free conference!
Could this clinical trial help you? If you have MDS in the Low- or Intermediate-Risk category, and you are transfusion-dependent, please refer to this information to discover if it might be for you!


COVID-19 and Resuming Clinical Visits: Frequently Asked Questions

You can find the advice that clinics are using to reopen in this time of the COVID-19 pandemic. Learn more about how they are working to protect you

HERE.

July Webinars

July 7, 2020, at 8:00 pm EDT: **Coping with the Fear of Recurrence** - Mary Hughes, MS, RN, CNS, CT, of MD Anderson Cancer Center will share coping strategies that patients can use to lessen the fear of disease recurrence as they adjust to life after diagnosis and treatment. Please register HERE.

July 8, 2020, at 2:00 pm EDT: **Hereditary Predispositions to MDS** - Sarah Bannon is a Senior Genetic Counselor in the Department of Clinical Cancer Genetics at the UT MD Anderson Cancer Center. She will discuss hereditary or genetic predisposition to having MDS. Please register HERE.
July 10, 2020, at 11:00 am EDT: **Relapse Prevention in Patients with Severe Aplastic Anemia** - Dr. Bahvisha Patel of the NIH will discuss best practices in preventing relapse for patients with Severe Aplastic Anemia. There will be an opportunity for participants to ask questions of Dr. Patel. Please register [HERE](#).

July 10, 2020, at 2:00 pm EDT: **Treating MDS with Combination Therapies** - Dr. Sharon McCurdy of Penn Medicine will discuss treating MDS (myelodysplastic syndromes) with combination therapies including the latest treatment options available and promising clinical trials and research. Please register [HERE](#).

July 28, 2020, at 3:00 pm EDT: **Autoimmune Disorders and MDS** - Dr. Carlos E. Vigil of the University of Iowa Hospitals and Clinics will discuss autoimmune disorders and MDS (myelodysplastic syndromes) including an assessment of the overlap between autoimmune disorders and bone marrow failure disease, the impact this can have on treatment options and on patient prognosis. Please register [HERE](#).

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**AAMDSIF Awards 2019-2021 Grant to Children’s Hospital of Boston Researcher**

One of two 2019-2021 two-year research grants of $30,000 per year has been awarded to Elissa Furutani, MD, of Children’s Hospital of Boston, for her proposed research project, *Risk stratification for genetic causes of severe aplastic anemia*. Support for this grant was generously provided by *The Julia Malsin Research Fund*.

Research Project Summary:

We propose a multi-institutional study of children and young adults presenting with Severe Aplastic Anemia (SAA). We will study patients’ medical records and run genetic testing to look for inherited causes of aplastic anemia to describe how often patients with SAA have an inherited disorder. We will describe which patients are at a higher risk of having such an inherited disorder and therefore which patients would benefit from undergoing genetic testing. As part of this research effort we may also be able to discover new genetic causes of aplastic anemia as well.

“We’re pleased to be able to offer this research grant to Dr. Furutani,” said Neil Horikoshi, AAMDSIF’s CEO and Executive Director. “This research project is aligned with an important part of our mission – being part of the solution for research and eventual cures for aplastic anemia.”

*This AAMDSIF Research Grant is supported by the Julia Malsin Research Fund, established by Heather and Michael Malsin in memory of their daughter, Julia, who lost her battle against aplastic anemia.*

*Throughout her year-long illness, Julia inspired countless people, those who*
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grace and courage. Julia passed away on January 27, 2012, following complications from her bone marrow transplant. Our hope is that with continued research and funding, one child’s life may be saved and one family will not have to endure the pain and suffering that aplastic anemia brought into our lives. Her story continues to inspire others and her legacy continues through what has become known as the Julia Effect.

About AAMDSIF

The Aplastic Anemia and MDS International Foundation (AAMDSIF) is the world’s leading nonprofit health organization dedicated to supporting patients and families living with aplastic anemia, myelodysplastic syndromes (MDS), paroxysmal nocturnal hemoglobinuria (PNH), and related bone marrow failure diseases. AAMDSIF provides answers, support and hope to thousands of patients and their families around the world.

Over the past 31 years, AAMDSIF has provided over 5 million dollars in financial awards to researchers for investigation that leads to new insights into the causes and treatment of bone marrow failure disease and the development of new therapeutic approaches.

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