



FOUNDATION Update

Connecting Patients and Families with News and Expert Opinion



You Gave Hope on Giving Tuesday!

Over 150 generous supporters donated **\$10,176** towards the support of patients in need of hope! You gave patients opportunities to gain a greater understanding of their disease through AAMDSIF Webinars, Patient and Family Conferences, and a network of other patients and family members.

Your gifts raised funds to extend the research projects that have provided breakthrough innovation as well as help springboard the careers of professionals pursuing a cure for bone marrow failure diseases.

You've made it possible to provide answers, support and hope to patients and families living with bone marrow failure through your compassionate gifts.

We are so very thankful to you all. If you would like to make an additional gift or join the many generous people who have already contributed, simply click [here](#) or call the office at (301) 279-7202.

NEW Patient Education Materials:

[Blood and Bone Marrow Basics \(December 2019\)](#)



www.aamds.org

[MDS Patient Guide: Italian](#)

[AML Patient Guide: Italian](#)

We are pleased to provide our patients, families and caregivers with new resources. First, we have developed a new publication called **Blood and Bone Marrow Basics** to help explain the complex issues facing those affected by bone marrow failure disease. With expert guidance from Andrew M. Brunner, M.D. with Massachusetts General Hospital, this patient guide was developed with input from patients, family members and caregivers and edited by AAMDSIF's Patient Education Council.

Second, we are extremely grateful to long-time volunteer Bill Hamm and to our colleagues with the [Associazione Italiana Pazienti con Sindrome Mielodisplatica](#) for their extraordinary efforts in translating both our **MDS and AML Patient Guides**.

You can download your free copy [online](#) or request that a copy be sent to you at your home. We can also provide bulk copies for our health care provider partners. To request a printed copy, please send an email to help@aamds.org.



AAMDSIF Announces 2020 Patient & Family Conference Locations!

We're heading to Atlanta, Seattle and Cleveland this year for our regional conferences and our National Conference will be just outside Washington D.C. in Bethesda, MD

We are delighted to announce our 2020 schedule of Patient & Family Conferences which will be held concurrently with educational symposia for health care professionals.

April 18, 2020: Atlanta, Georgia

June 20, 2020: Seattle, Washington (at the Fred Hutch)

July 17 - 19, 2020: Bethesda, Maryland (National Conference)

October 3, 2020: Cleveland, Ohio

We will open up registration in early 2020. Stay tuned for registration information, faculty details and expanded agendas with educational opportunities for young adults, elders and more!



Last Chance to Enroll in MDS Clinical Trial!

A Phase III, International, Randomized, Controlled Study of Rigosertib versus Physician's Choice of Treatment in Patients with Myelodysplastic Syndrome after Failure of a Hypomethylating Agent

If you or someone you love has higher risk MDS and has not successfully responded to certain treatments, Onconova is finalizing enrollment in a Phase III clinical trial. There are a number of factors to consider when enrolling in a clinical trial and we encourage all of our patients, families and caregivers to speak with their health care provider(s) prior to enrollment. Click [here](#) to learn more about the trial and to see if you meet the eligibility requirements.



AAMDSIF Attends the American Society of Hematology Annual Meeting

Learning about new treatment options, providing important education for health care professionals!

AAMDSIF actively participated in the American Society of Hematology Annual Meeting, held December 7 – 10 in Orlando, Florida, to learn the latest information on aplastic anemia, MDS, PNH and related diseases. Attended by nearly 30,000 from around the world, the ASH annual meeting is an invaluable educational experience for hematologists/oncologists, patient advocates, pharma companies and others interested in the most up-to-date scientific and clinical research. Here's a quick summary of what AAMDSIF did at ASH:

Satellite Symposium – AAMDSIF in partnership with Cleveland Clinic sponsored a three-hour symposium on the Clinical Management of Myeloid Malignancies featuring an

outstanding international faculty of experts. We recorded interviews with all six speakers to share the highlights of their presentations with patients – look for these to be posted soon on social media and our website.

Poster/Oral Abstract Presentations, Education and Scientific Sessions - Investigators selected to present their findings at ASH share their discoveries with other researchers and discuss future opportunities, and AAMDSIF selects the most relevant updates to share with patients in upcoming webinars and publications.

Exhibit – The AAMDSIF exhibit at ASH builds awareness about our patient education resources and support for patients, as well as our professional education programs and research grants. We encourage our exhibit visitors to connect their patients directly with us so we can address their specific needs.

In early 2020, stay tuned for a series of publications and webinars all about ASH and what's new in treatment options for bone marrow failure diseases.



AAMDSIF Announces New Medical Advisory Board Members

AAMDSIF's Medical Advisory Board meets annually to provide insight and guidance on future programming and initiatives as well as to receive an update on the year's activities. During the in-person meeting this month, we welcomed five new members to the MAB:



David Araten, MD, New York University



Rami Komrokji, MD, Moffitt Cancer Center, Florida



**Kinuko Mitani, MD, PhD,
Dokkyo Medical University,
Japan**



**Uwe Platzbecker, MD, University
Hospital, Leipzig, Germany**



**Phillip Scheinberg, MD,
University of Sao Paulo, Brazil**



AAMDSIF: Investing in Research Research is Happening Across the Globe

Dr. Kuziko Ikeda was awarded an AAMDSIF research grant in 2009 when he was working at Washington University in St. Louis with Dr. Monica Bessler, a former AAMDSIF grantee.

Before obtaining an AAMDSIF grant, researchers like me“ were anxious about the future, because research funding was being scaled back in the wake of a global economic crisis. So, news of this grant award was a source of great joy ”.and great relief

Thanks to the ‘international’ aspect of this grant, AAMDSIF“ support could follow me, from Washington University in St. Louis and Children’s Hospital of Philadelphia, back to Fukushima Medical University in Japan. This grant also encouraged me to initiate new research in 2011, even as Japan's earthquake, tsunami, and nuclear crisis especially ”.affected Fukushima

The concept of clonal dominance by HMGA2 has been one of Dr. Ikeda’s major interests in his research career, and he said the AAMDSIF grant “provided me the opportunity to obtain several more research grants, and research support from AAMDSIF was a deciding factor in deliberations that led to my promotion to full professor and appointment as a department chair.

Dr. Ikeda shared a “small world” anecdote, noting that when he attended the AAMDSIF Scientific Symposium in 2010, **AAMDSIF's CEO Neil Horikoshi** (then the board chairman) “kindly took time to speak with me and it was a

motivational coincidence to learn that he traced his ancestry to Fukushima!”

When asked what it means to him as a researcher to know that the grant funds are raised by patients, families, and communities, Dr. Ikeda said “they empower investigators to move forward. My research is driven by the hope of helping patients, sooner rather than later. MPN-JAPAN, a community of patients with MPN and their families, has included me on their medical advisory board. I sometimes give lectures and answer questions from patients and families in meetings of MPN-JAPAN and another non-profit organization, Tsubasa, which provides information on wide variety of hematologic diseases including bone marrow failure. Moreover, I continue to be involved in direct patient care. These associations and activities motivate me to continue the research.”



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