This report is a summary of the work made possible through your support!
A MESSAGE FROM OUR CEO ON THIS UNFORGETTABLE YEAR

Just as 2020 was an incredibly complex year, it was clear that this year’s Impact Report could not be business as usual. In addition to recognizing the accomplishments of our community and our staff, so much due to the strong support from our sponsors and donors, we need to recognize the challenges and opportunities we faced keeping all our constituents safe and healthy by going virtual for all AAMDSIF’s activities, from webinars and conferences to walks and support groups.

Like the world, AAMDSIF will never be the same. We are so pleased and grateful for the outreach and the impact we made in becoming more accessible to so many more patients, family members, caregivers and medical professionals. Hybrid events will continue to be the best way to reach the most people. We will continue to maximize the world’s increased empathy towards the vulnerability and challenges our patients have always faced with their diagnoses and treatments. We will continue to look for avenues to provide better education, access to information and support so that early and equitable diagnosis and treatment options are available to all our diverse patient groups.

Some things have not and will not change. Our loyal and steady volunteers, donors and champions continue to buoy the work our staff does every day. We could not do this work without you. Our devotion to our patients, putting them first and providing them with the most up-to-date research and disease news informed by our dedicated Medical Advisory Board of international bone marrow failure experts, is core.

Our committed and supportive Board of Directors, who donate their time, experience and knowledge to ensure that AAMDSIF continues to grow, will provide the needed leadership for the organization.

We know that growth sometimes entails pain. This year we have experienced both. We grew as an organization from facing our collective challenges together, and we will be more able to serve our patients and their families because of the adaptability this year demanded.

Thank you for your continued support and for welcoming me so generously and warmly into the AAMDSIF family.

Please enjoy this year in review; I welcome your feedback.

In appreciation,

Janice Frey-Angel
CEO of AAMDSIF
THE MISSION

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

THE VISION

We are a patient-focused, patient-centered organization, serving patients and families throughout the three phases of bone marrow failure diseases:

- The life changing phase of diagnosis
- The life threatening phase of treatment
- The life long phase of living with a chronic disease

AAMDSIF REPRESENTS COMMUNITY

AAMDSIF represents a community, passionately committed to supporting patients and families and finding a cure for bone marrow failure diseases. No one is immune to bone marrow failure, it can strike any gender, at any age, regardless of race or ethnicity.
AWARENESS & PATIENT SUPPORT

1.4 Million unique page views

1.2 Million users

17,745 Patients and families served

6,291 Viewers for online learning including webinars

5,735+ hours of our videos watched

3 Patient & Family Conferences, hosting 1,737 attendees

Over 5,028 Patient Education Materials Downloaded

127 support groups
In 2020, AAMDSIF made the decision to take our Patient & Family Conferences virtual in order to protect our patients, family members, caregivers, faculty and staff. We were able to come together for two one-day events in the Spring and Fall and for a three-day Global Conference in the summer with more than 1,700 participants.

““This has been my first AAMDSIF conference and I have gotten a lot of valuable information from the speakers. Love the ability to go back and watch sessions I’ve missed or watch some a second time. I look forward to attending a live conference in the future. Thanks so much for making this happen!””
- Janet (Attendee)

The conferences have been an important source for education and networking since 2002.

Approximately 19% of our Conference attendees were from outside the U.S. and represented 46 countries across the globe.

“I learn something new with every presentation! AAMDSIF is the best source for patient info and support”” - Nicholas (Attendee)
For more than 30 years, the Foundation has provided investigators with financial support for research that leads to new insights into the causes of bone marrow failure and the development of new therapeutic approaches.

Members of the AAMDSIF Medical Advisory Board review the applications, awarding grants based on the scientific quality of the research plan, the relevance of the proposed research to the Foundation’s goals, the applicant’s qualifications, and the quality of the research institution and facility where the study will be conducted.

In 2020, two grantees were awarded $60,000 each for their two-year research studies. The funds that support these grants have been generously provided by patients, families and friends affected by bone marrow failure diseases.

**The AAMDSIF Research Grant Program**

**VALENTINA GUIDICE, MD**  
(University of Salerno)

**Low-Density Granulocytes and Neutrophil Extracellular Traps in AA and MDS**

Support generously provided by the Amy Gaynor Research Fund

**AUDREY LASRY, PHD**  
(NEW YORK UNIVERSITY SCHOOL OF MEDICINE)

**Single Cell Mapping of Bone Marrow Microenvironment During MDS to AML Transition**

Support generously provided by the Harold Spielberg Research Fund
AAMDSIF presented the Seventh International Bone Marrow Failure Scientific Symposium virtually on July 15, 16 & 17, 2020. Once again, this biennial Symposium brought together many of the world’s leading experts on the biology and treatment of aplastic anemia, myelodysplastic syndromes, paroxysmal nocturnal hemoglobinuria, acute myeloid leukemia and related disorders. As a result of the virtual format due to the coronavirus pandemic, our registration was higher than ever, with over 750 participants from 38 nations.

We are most grateful to the co-chairs of this event, Richard Stone, MD of Dana-Farber Cancer Institute and Neal Young, MD, of the National Heart, Lung, and Blood Institute, and to the outstanding session co-chairs with whom they worked to plan and organize the Symposium. The presentations by the internationally respected faculty stimulated discussion and provided new insights for future studies. This year the virtual platform enabled hundreds more new investigators and those from distant countries to participate, making it a truly global event.

As always, AAMDSIF also shared the latest research presented at the symposium with patients through recorded interviews by the symposium session co-chairs and a Summary for Patients booklet with lay language reports on every symposium presentation.

These resources continue to be accessible on our website.

The Symposium would not have been possible without the generous contributions from our sponsors, listed in this report. The ongoing collaborative effort of academia, government, private industry and AAMDSIF demonstrates the mutual commitment to the discovery of new treatments for patients, and ultimately, cures for bone marrow failure diseases.
Volunteer-driven events are a crucial part of raising awareness for rare bone marrow diseases and supporting the search for a cure. These events build upon the understanding of the diseases and lead to more funds dedicated to patient support and research. We had more than 400 participants in 4 states, raising more than $120,000 for patient education and research.

These volunteer events are designed to ensure that anyone, anywhere can participate virtually.

March for Marrow and grassroots events around the country helped raise awareness for bone marrow failure diseases, one community at a time.

Other community fundraisers included Golf Tournaments, Facebook Fundraisers, and virtual events dedicated to raising funds for patients and families living with bone marrow failure.
Fred Vendig’s Story: Told by Stephanie Vendig

We support the Aplastic Anemia and MDS International Foundation because they helped our family as my husband, Fred, struggled with MDS. Until his passing, they were part of our support system as we fought the disease together.

Fred was diagnosed with Myelodysplastic Syndromes (MDS) at a routine physical when he was 60. They told Fred that he would only live 18 months to 5 years, and there was no cure. We received little information about the disease or possible treatments since the disease is so rare.

The MDS diagnosis was earth-shattering. Fred had no collection of symptoms that would have prepared us for the life-threatening condition. We had planned a retirement full of travel and hobbies instead of rocking chairs, and suddenly those plans evaporated. We both had enjoyed good health all our lives, so we were shaken.

We decided not to mark time as Fred’s condition progressed, but instead to take action, no matter the outcome. Since our children were grown, we could concentrate on fighting MDS.

As a survivor of the Holocaust, my husband learned early that he shouldn’t only rely on himself alone. First, I ran to the local library to gather all the information I only found listings of academic papers in this pre-internet era. Next, we sought a second opinion, which confirmed the diagnosis. The doctor did help with a recommendation of a clinical trial that featured a drug targeting MDS.

As we searched for answers, we found the Aplastic Anemia and MDS International Foundation (AAMDSIF) to be a source for information and other resources. As the internet became a fixture in our lives, AAMDSIF’s web-based help became a valuable part of our support system.

AAMDSIF gave us the chance to meet other people “in the same boat” at their patient and family conferences. At one conference, I met a man whose wife also had MDS. He had a listserv for patients and families all over the world, who shared their information on MDS as well. Through these patient conferences and the listserv, we began to feel that we were not helpless victims of the disease.
Fred participated in two more clinical studies with the NIH. We learned that he could have a bone marrow transplant as a possible solution. When his brother was tested, we were disappointed that he was not a match for Fred. (After his death, we discovered that Fred’s brother was also diagnosed with MDS. If he had been a match, then Fred would have received cells contaminated with the disease.)

We moved to Seattle, Washington, to take advantage of the bone marrow transplant program at Fred Hutchinson Cancer Care Facility there. The procedure was successful.

Then Fred’s condition took a turn for the worse. With a reduced immune system from the transplant and an antibiotic-resistant bacterium, the infection quickly overwhelmed his system.

After 17 days of a successful transplant and 8 years of fighting MDS, Fred lost his battle on September 14, 2001 of methicillin-resistant Staphylococcus Aureus, or MRSA.

Even after losing my beloved husband, our family continues to give to AAMDSIF in support of other MDS patients and those with other bone marrow failure diseases. Join me in providing support for these invaluable patient support services, including patient and family conferences, health professional resources, and scientific research.

Sincerely,
Stephanie Vendig
Spouse of MDS Patient, Fred Vendig
# Meet Our 2020 Corporate and Funding Partners

<table>
<thead>
<tr>
<th>Company Name</th>
<th>Foundation Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>AbbVie</td>
<td>Henry &amp; Marilyn Taub Foundation</td>
</tr>
<tr>
<td>ABC13</td>
<td>Herman Goldman Foundation</td>
</tr>
<tr>
<td>Acceleron</td>
<td>I L Cohen Foundation</td>
</tr>
<tr>
<td>Agios</td>
<td>James A Reep Family Foundation</td>
</tr>
<tr>
<td>Alexion</td>
<td>Jazz Pharmaceuticals</td>
</tr>
<tr>
<td>AltaMed Health Service Corporation</td>
<td>Kass Family Foundation</td>
</tr>
<tr>
<td>Amos &amp; Ruth Wilnai Foundation</td>
<td>Mia Hamm Foundation</td>
</tr>
<tr>
<td>Apellis</td>
<td>Novartis</td>
</tr>
<tr>
<td>Aprea</td>
<td>Onconova Therapeutics</td>
</tr>
<tr>
<td>Bristol Myers Squibb</td>
<td>Pan Foundation</td>
</tr>
<tr>
<td>Costco Wholesale</td>
<td>Pharmerit</td>
</tr>
<tr>
<td>Edward P. Evans Foundation</td>
<td>Regeneron</td>
</tr>
<tr>
<td>Everylife Foundation</td>
<td>S&amp;P Global Foundation</td>
</tr>
<tr>
<td>Genentech</td>
<td>Snow Family Foundation</td>
</tr>
<tr>
<td>Geron</td>
<td>Taiho Oncology</td>
</tr>
<tr>
<td>Harold Raisler Foundation</td>
<td>Takeda Oncology</td>
</tr>
</tbody>
</table>
## Meet Our 2020 Patient & Educational Partners

| American Academy of Nurse Practitioners | Maddie Riewoldt’s Vision |
| American Society of Hematology          | Mayo Clinic Jacksonville |
| The Assistance Fund                      | MDS Alliance             |
| Be The Match                             | Medical Learning Institute|
| BMT InfoNet                              | MPN Research Foundation  |
| Cleveland Clinic Taussig Cancer Institute| National Comprehensive Cancer Network (NCCN) |
| Fanconi Anemia Research Fund             | National Organization of Rare Diseases (NORD) |
| GRYT Health                              | Oncology Nursing Society |
| HealthWell Foundation                    | Patient Access Network Foundation |
| i3 Health                                | University of New Mexico |
| Imedex                                   | University of South Florida |
| Leukemia & Lymphoma Society              |                         |
Meet Our 2020 Board Of Directors

Chairman: Kevin Lyons-Tarr
Vice Chairman: Harsha Murthy
Secretary: Stephen King
Treasurer: Tony Sanfilippo
CEO & Executive Director: Neil Horikoshi

Board Members:
Deborah Ziff Cook
Bart Fisher
James Gajewski, MD
Stephanie Dillon Hamm
Melanie Marquez
Judy Paulette
Saira Sufi
Rebecca Doane
Meet Our 2020 Medical Advisory Board

Chair
Mikkael Sekeres, MD, MS
Sylvester Comprehensive Cancer Center, University of Miami

Vice Chair
Olatoyosi Odenike, MD
University of Chicago

Members
David Araten, MD
NYU Hematology Associates
Pamela Becker, MD, PhD
University of California Irvine
Carlos M. de Castro, III, MD
Duke University Medical Center
H. Joachim Deeg, MD
Fred Hutchinson Cancer Research Center
Amy E. DeZern, MD, MHS
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
Benjamin L. Ebert, MD, PhD
Dana-Farber/Harvard Cancer Center
Guillermo Garcia-Manero, MD
MD Anderson Cancer Center
Aristoteles Giagounidis, MD, PhD
Marienhospital-Dusseldorf, Germany
Steven D. Gore, MD
National Institutes of Health
Timothy Graubert, MD
Massachusetts General Hospital Cancer Center
Rami Komrokji, MD
Moffitt Cancer Center
James Letterio, MD
Case Western Reserve University
Rainbow Babies and Children’s Hospital
Jaroslaw P. Maciejewski, MD, PhD
Cleveland Clinic
Taussig Cancer Center
David Margolis, MD
Medical College of Wisconsin
Kinuko Mitani, MD, PhD
Dokkyo Medical University School of Medicine, Tochigi, Japan
Stephen D. Nimer, MD
Sylvester Comprehensive Cancer Center, University of Miami
Ronald Paquette, MD
Cedar-Sinai Medical Center
Gail J. Roboz, MD
Weill Medical College of Cornell University
Uwe Platzbecker, MD
University Hospital Leipzig, Germany
Valeria Santini, MD
University of Florence, Italy
Phillip Scheinberg, MD
Hospital Sao Jose, Beneficencia Portuguesa de Sao Paolo, Brazil
B. Douglas Smith, MD
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
Richard Stone, MD
Dana-Farber Cancer Center
Neal Young, MD
National Institutes of Health
Meet Our 2020 Volunteer Patient Education Council

Isabel Schuermeyer, MD (Chair)

Members:
Benton A. Berman
Taylor Buss, MSW
Tom Clark
Ellen Conybear
Paige Cranwell
Robert Delfeld
Ron Duncan
Inga Hoffman Zhang, MD, PhD
Brandi Lewis
Hemant Murthy, MD

Joanna Myers Casale, RD, CSO
Ryotaro Nakamura, MD
Shyamala Navada, MD
Sandrine Niyongerre, MD
Joan Powell
Olga Rios, R.N.
Mario Rivera
Lydia Seiders
Saira Sufi
Barbara Weinstein, BSN
Korey Yamagata
AAMDSIF is a 501(c)(3) nonprofit charitable organization that raises its annual operating budget from individuals, fundraising events, corporations and private foundations. 81% of our support is dedicated to providing education, information and research.

2020 AUDITED REVENUE

- Corporate and Other Grants: 57%
- Individual Foundation Donations: 40%
- Interest and Other Income: 3%

Total Revenue: $2,628,588

2020 AUDITED EXPENSES

- Program Services: 81%
- Support Services: 19%

Total Expenses: $2,388,116

$1,871,228

$148,035

$560,181
THE POWER OF COMMUNITY SUPPORT

The support of patients, family members, and friends is what makes it possible for AAMDSIF to provide answers, support and hope to patients and families fighting bone marrow failure diseases. Private support provides for the education, information, and resources describing these diseases and treatment options. Community funds raised also support research funds for young investigators. THANK YOU!

Gifts are received from dedicated individuals and corporate support, through various community events and fundraisers, along with gifts made in tribute, memory and honor of loved ones. Each and every gift makes a difference in the life of someone diagnosed with a bone marrow failure disease.

We are very grateful to all of our donors and their support of our mission.
Please support AAMDSIF as often and as generously as you can. Each gift makes a difference to someone in our community.

You can trust AAMDSIF to use your funds wisely - in 2020 we spent 81% of our resources serving patients with support, education, and research.

AAMDSIF is a 501(c)3 charity. Your gift is tax-deductible as allowed by U.S. law.

4330 East West Highway, Suite 230
Bethesda, MD 20814
help@aamds.org
www.aamds.org