



**Aplastic Anemia and MDS  
International Foundation**

# **2020 ANNUAL REPORT YOUR IMPACT**

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

# Virtual Patient & Family Conferences

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)**



# 2020 Research Grant Recipients

## The AAMDSIF Research Grant Program

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.



**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

# PROFESSIONAL EDUCATION

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.

## 2020 SCIENTIFIC SYMPOSIUM OVERVIEW



## TREATMENTS FOR MDS AND SECONDARY AML



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.

# COMMUNITY EVENTS AND BUILDING AWARENESS



AA • MDS INTERNATIONAL FOUNDATION

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.



Photographs from L.A. Event held Pre-Pandemic



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.



## WHY WE GIVE

# PATIENT STORY

## 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.

**We thought “if we could do something, we should do something!”**

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.

# PATIENT STORY

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.)

**Through the Foundation we learned about donor registries, and we found a match.**



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**

AbbVie

ABC13

Accelaron

Agios

Alexion

AltaMed Health Service  
Corporation

Amos & Ruth Wilnai Foundation

Apellis

Aprea

Bristol Myers Squibb

Costco Wholesale

Edward P. Evans Foundation

Everylife Foundation

Genentech

Geron

Harold Raisler Foundation

Henry & Marilyn Taub  
Foundation

Herman Goldman Foundation

I L Cohen Foundation

James A Reep Family  
Foundation

Jazz Pharmaceuticals

Kass Family Foundation

Mia Hamm Foundation

Novartis

Onconova Therapeutics

Pan Foundation

Pharmerit

Regeneron

S&P Global Foundation

Snow Family Foundation

Taiho Oncology

Takeda Oncology

## Meet Our 2020 Patient & Educational Partners

American Academy of Nurse Practitioners

American Society of Hematology

The Assistance Fund

Be The Match

BMT InfoNet

Cleveland Clinic Taussig Cancer Institute

Fanconi Anemia Research Fund

GRYT Health

HealthWell Foundation

i3 Health

Imedex

Leukemia & Lymphoma Society

Maddie Riewoldt's Vision

Mayo Clinic Jacksonville

MDS Alliance

Medical Learning Institute

MPN Research Foundation

National Comprehensive Cancer Network (NCCN)

National Organization of Rare Diseases (NORD)

Oncology Nursing Society

Patient Access Network Foundation

University of New Mexico

University of South Florida



## 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

# The Strength Of **Partnerships**

## **Meet Our 2020 Medical Advisory Board**

### **Chair**

Mikhael 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

Jaroslav 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 Paulo, 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)

Joanna Myers Casale, RD, CSO

**Members:**

Ryotaro Nakamura, MD

Benton A. Berman

Shyamala Navada, MD

Taylor Buss, MSW

Sandrine Niyongerre, MD

Tom Clark

Joan Powell

Ellen Conybear

Olga Rios, R.N.

Paige Cranwell

Mario Rivera

Robert Delfeld

Lydia Seiders

Ron Duncan

Saira Sufi

Inga Hoffman Zhang, MD, PhD

Barbara Weinstein, BSN

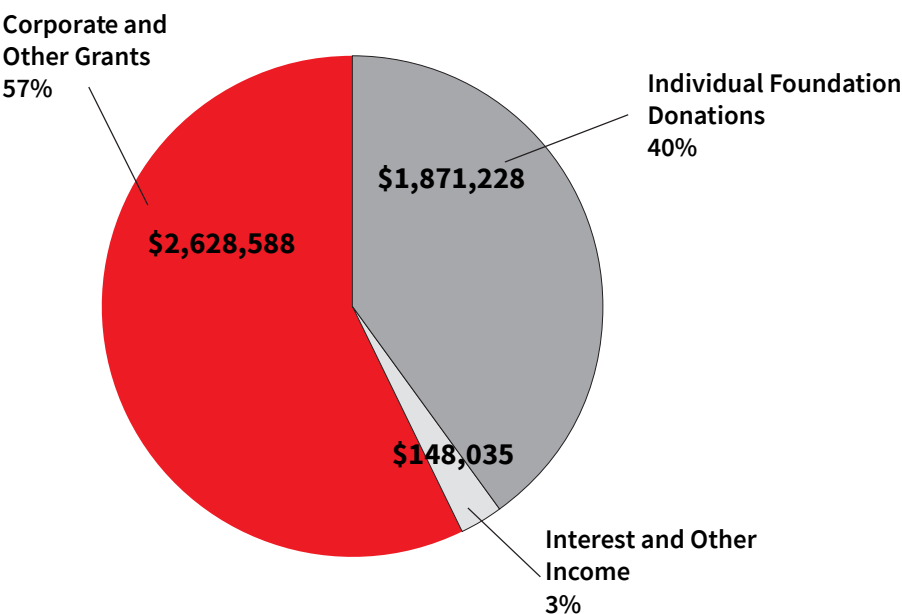
Brandi Lewis

Korey Yamagata

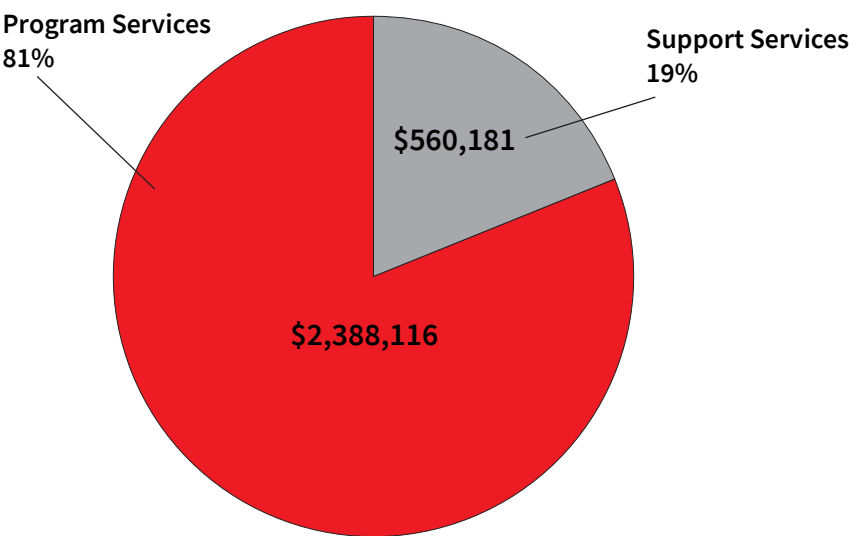
Hemant Murthy, MD

# 2020 Financial Statements

## 2020 AUDITED REVENUE



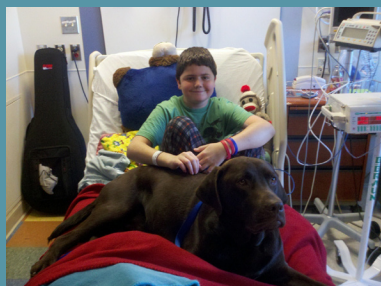
## 2020 AUDITED EXPENSES



*AAMDSIF is a 501(c)(3) nonprofit charitable organization that raises our annual operating budget from individuals, fundraising events, corporations and private foundations. 81% of our support is dedicated to providing education, information and research.*



# 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](http://www.aamds.org)