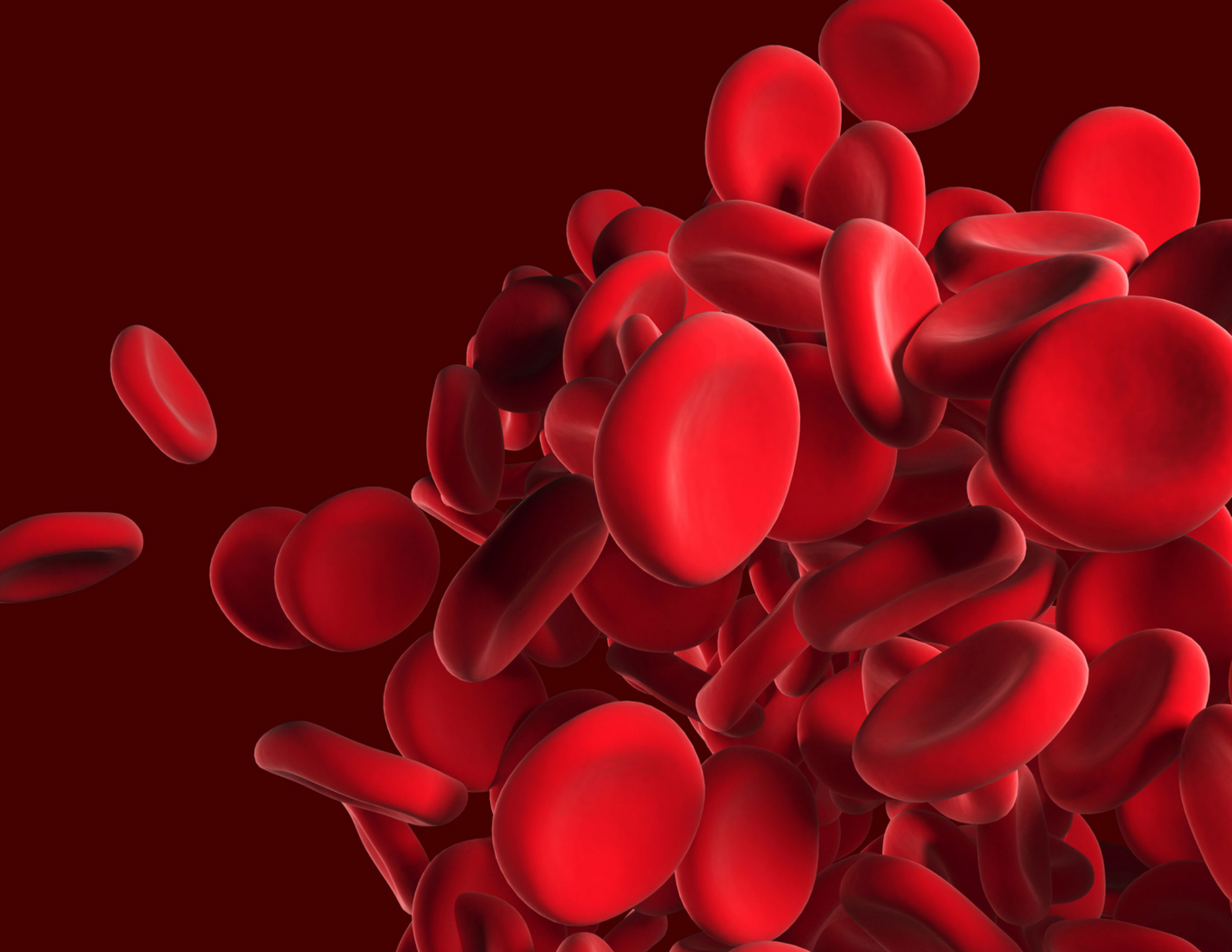




Aplastic Anemia and MDS  
International Foundation  
2021 Impact Report









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# MEET— JOAN POWELL

## MOTIVATION

In 2014, Joan was busy handing out candy to the tiny ghouls and goblins of her neighborhood, but the scariest thing that Halloween was a phone call.

Her doctor told her to take a break from trick-or-treaters and sit down for what came next. As Joan's heart began to pound, her doctor delivered the diagnosis. Joan had myelodysplastic syndromes or MDS. Joan was so shocked that she asked her doctor to spell out myelodysplastic four times.

After some time of grieving and acceptance, Joan became proactive. She searched the internet for information about her life-changing diagnosis and came across the Aplastic Anemia and MDS International Foundation. She began to attend conferences to learn more about the disease, and from there, she knew that many others like her were diagnosed with MDS and her journey felt a whole lot less lonely.

Today, Joan is a powerhouse in advocating for her condition, treatment, and the advancement of scientific research. She's traveled, in her words, "from the beaches of California to the Capitol steps" as an advocate for patients with MDS. Since 2015 Joan has been a volunteer Patient Advocate and member of the Patient Education Council for the Aplastic Anemia and Myelodysplastic Syndromes International Foundation. She was recently appointed an AAMDSIF Support Group Facilitator for the Western United States.

Joan believes her role as a patient advocate is vital as an African American woman since African Americans are underrepresented at advocacy events. Above all, Joan wants others to know they aren't suffering alone—that she is with them.

Joan credits AAMDSIF for supporting her through her roller coaster MDS journey.

Watch the video of Joan's story [here](https://bit.ly/3Ny5Rsl)  
<https://bit.ly/3Ny5Rsl>



**In 2021, 871 individuals participated in one of AAMDSIF's support groups.**



## MEET BRIANA DONIS

Briana Donis was having a pretty awesome year. She was very well known at school and had been voted Homecoming queen, and she had a boyfriend. She had just been accepted at the college of her choice when she noticed how really tired she was all the time. And then the bleeding started. Briana noticed that even a small paper cut would fill a napkin with blood. She thought it was weird and went to see her doctor. Briana's life changed in an instant.

Briana was diagnosed with severe aplastic anemia, but the 18-year-old had no way of knowing how serious it was. Briana had no idea that she would soon be fighting to save her own life. Briana was no longer able to attend school, which meant she had to miss prom...and college had to wait. Immunosuppressive therapy was the first course of treatment, but it didn't work in Briana's case. She would need to prepare herself for a bone marrow transplant. There was no DNA match in Brianna's immediate family but, amazingly, the National Bone Marrow Registry came up with five unrelated donor matches. Even so, Briana's first transplant was unsuccessful. She would have to go through the process all over again. Thankfully, Briana's second transplant worked.

A hallmark of Briana's nature is her firm belief that everything happens for a reason. That trait gave her the significant advantage of being able to accept and cope with her situation. Optimism can't be taught, but Briana had it in abundance. "Once I could do that for myself, I was happy. I was excited to see where this would take me and what doors would open because of it." One of those doors was AAMDSIF, which Briana connected with for the information, resources, and support she and her family needed. Briana's illness did bring opportunity.

Briana was nominated to be the featured champion at the Houston Frontier Fiesta March for Marrow event. "I believe this really is raising awareness," said Briana. "It's such an important thing to do because most people don't know about severe aplastic anemia, MDS and PNH."

Briana has some very straightforward advice for people who want to support bone marrow failure patients: "Donate, donate, donate. If you can't give money to AAMDSIF, give of yourself."

Watch the video of Briana's story [here](https://bit.ly/3NkqhEI)  
<https://bit.ly/3NkqhEI>

**In 2021 volunteers across the country hosted 6 March for Marrow Runs & Walks with more than 369 participants coming together to help raise funds and awareness for patients like Briana!**

## A MESSAGE FROM OUR CEO

You remember who showed up for you when you needed them most.

In 2021, you showed up for us, motivating us as we provided answers, support, and hope to thousands of patients and their families. Your commitment to our mission humbled us. Thank you.

Despite its challenges and hardships, the trials of 2021 also served as an engine for creative solutions, expanded programs, sound financials, and an unyielding dedication to our mission. We were reminded that transformative change is possible by centering on patients and their needs.

I feel immense satisfaction in what we accomplished together in 2021. I am excited about the new opportunities to expand our reach to patients and families and bring more people into our community of donors and supporters.

One of our values is building and maintaining relationships. We've had the pleasure of partnering with many corporate, foundation, and educational partners over the years, and we are eager to expand our partnerships to include medical institutions.

We are redesigning our website to mirror the patient and family experience of diagnosis, treatment, and living with aplastic anemia, myelodysplastic syndromes, and/or paroxysmal nocturnal hemoglobinuria. Our goal is for you to find the answers easily, sometimes before you've even asked the question.

2021 brought us a deluge of unique opportunities to learn and connect and has shaped our vision for AAMDSIF's future. I invite you to look back at the past year and what it has meant to AAMDSIF. As you read through the pages and find inspiration in these stories, I hope you will pause to celebrate the milestones your support made possible. My thanks again.

Sincerely,

Janice Frey-Angel  
Chief Executive Officer



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 worldwide.

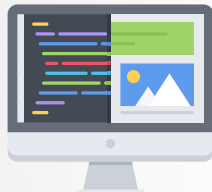


# IN 2021

AAMDSIF reached patients and families in the following ways:

## 1,244,228

Unique  
website  
visitors



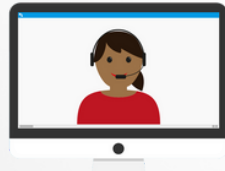
Nearly  
100,000  
views of  
content on  
YouTube!

Website  
visitors  
Top 10  
countries:

United States, India,  
United Kingdom,  
Canada, Australia,  
Philippines, France,  
Nigeria, Italy, Brazil

## 2,943

Webinar  
Participants



You can watch past webinar recordings  
[here](https://aamds.org/education/webinars) ([aamds.org/education/webinars](https://aamds.org/education/webinars))



## 7,430

Digital Patient  
Education Publications  
were downloaded and 423 new  
patient packets were mailed

## 86

Peer Support  
Network  
Volunteers

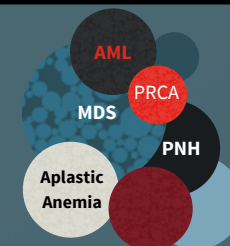


## 67

Support Group  
Meetings

## 5

Virtual Patient &  
Family Conferences





Each year, hundreds of volunteers get together and devote their free time to planning and participating in special events that raise much needed funds to drive our mission. Not even the pandemic could stop our dedicated volunteers, who in 2021 planned events ranging from golf tournaments and virtual walks to birthday fundraisers - that raised more than \$277,000.

## 369 Participants in 6 March for Marrow Events



New York/New Jersey  
March For Marrow Walk



Detroit, MI  
March For Marrow Walk



Los Angeles, CA  
March For Marrow Walk



Global Virtual  
March For Marrow Walk



Houston, TX  
March For Marrow Walk



Washington, D.C.  
March For Marrow Walk



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 research plan's scientific quality, 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.

## AAMDSIF 2021 Grant Recipients



**Salima Benbarche, PhD**

Memorial Sloan Kettering Cancer Center

Study Title: *Developing Synthetic Introns for Targeting Spliceosomal Mutant MDS*



**Sushree Sahoo, PhD**

St. Jude Children's Research Hospital

Study Title: *Mapping Clonal Ancestries in Pediatric MDS to Define Therapeutic Vulnerabilities*



# Health Professional Education

AAMDSIF provides professional education programs for health care providers who treat bone marrow failure patients so they can learn the latest information on diagnosis, treatment options, quality of life issues and patient needs.

In 2021 over 2,000 health care providers from more than 30 countries participated in professional education programs sponsored by AAMDSIF.



AAMDSIF presented a satellite symposium during the virtual annual meeting of the Oncology Nursing Society in May. This program was also available on-demand for ongoing access by nursing professionals.



In May AAMDSIF partnered with Platform Q Health to present a webinar for health professionals that featured recorded patient perspectives throughout the program.



For the 13th consecutive year AAMDSIF and Cleveland Clinic jointly sponsored a satellite symposium preceding the annual meeting of the American Society of Hematology.



## MEET JOE ELLENBERGER

Joe was diagnosed with PNH at 24 years old.

Joe, a wrestler had always been athletic. Joe was excited to expand his athletic capabilities and decided to transition from wrestling to mixed martial arts (MMA). It was during his tenth fight that Joe started to feel different. He was sluggish and tired and noticed that it took longer for his body to recover, and he had lingering abdominal and back pain. Joe thought nothing of it and continued his training routine and competitions going undefeated.

During a physical with his doctor, Joe discovered that his blood counts were out of whack and he was sent to a hematologist who ran some tests including a test for PNH, which came back positive. The hematologist knew Joe needed to find an expert and he also needed to learn everything he could about the condition.

Even though Joe was in denial, he did his research and found AAMDSIF and the PNH Foundation. And he found an expert -- after the first consultation with the expert, Joe knew he was facing something significant and could no longer be in denial. Joe felt reassured to have found an expert.

Joe was put on Warfarin to prevent clotting and later he started receiving infusions of Soliris®. Joe's treatment started working, and he was approved to go back to MMA and start competing again!

Joe encourages anyone who has recently learned they have PNH to try and do what he did. Get a specialist. Joe commented, "everyone experiences adversity – so even with what you are going through, try to be a source of support for others, no matter what their challenges are. I think some of what I learned as a wrestling team captain and later as an assistant coach helped me develop some of the personal skills I am using to live with PNH. As a team, we had upsets and defeats that were hard to face, but you dealt with them and lived to fight and compete another day. I used these same attitudes to deal with PNH."



**The AAMDSIF PNH Patient Travel Assistance Fund is available to U.S.-based PNH patients for up to \$500 per patient, per year, to see a PNH specialist or get a second opinion from a PNH specialist.**

## MEET SHIRLEY O'BRIEN

In February 2012, Shirley O'Brien was diagnosed with myelodysplastic syndrome (MDS), a disease that has no cure except for a stem cell transplant. Because she was in her mid-70s at the diagnosis, a bone marrow transplant wasn't the best option.

At the time of the diagnosis, Shirley and her spouse, Jim, had been retired from their jobs as professors at the University of Arizona for eight years. They were enjoying busy lives performing at festivals. They had a cruise planned, and although Shirley's oncologist encouraged them to take the cruise, they decided to cancel their trip and begin treatment immediately.

After seven months of treatment and being housebound, Shirley was given the news that there was no evidence of the disease, and she was in remission. However, Shirley remained cautiously optimistic. After consulting with some of the top MDS specialists in the nation, Shirley was told she needed to get back on her treatment plan. After two years of this treatment, Shirley's blood counts were still steadily moving lower. Eventually, doctors stopped her treatment, telling her it was no longer effective. It had failed. Shirley was given five to seven months to live unless she found a clinical trial soon. Shirley immediately got to work. She contacted AAMDSIF and heard back from the patient educator, who immediately sent Shirley five clinical trials. One trial at MD Anderson Cancer Center seemed like a good fit. Shirley applied to become a new patient at MD Anderson. Soon after, Shirley and Jim learned that Shirley's MDS had progressed to acute myeloid leukemia (AML). They were shocked but knew they were in the best place at MD Anderson.

Within six months, Shirley's blood count values had reached the near-normal range and were entirely normal within a year. The ongoing research that Dr. DiNardo is doing as part of MD Anderson's MDS/AML Moonshot is helping to ensure other patients will have this same opportunity.

Shirley has been in remission for the past seven years. She enjoys a full life of musical performance in Arizona in the winter and she and her spouse and their MinPin spend their summers together in Oregon.

Shirley is so thankful for the support she receives from AAMDSIF, the prayers of her friends and family, Dr. DiNardo, and her spouse Jim – her rock.



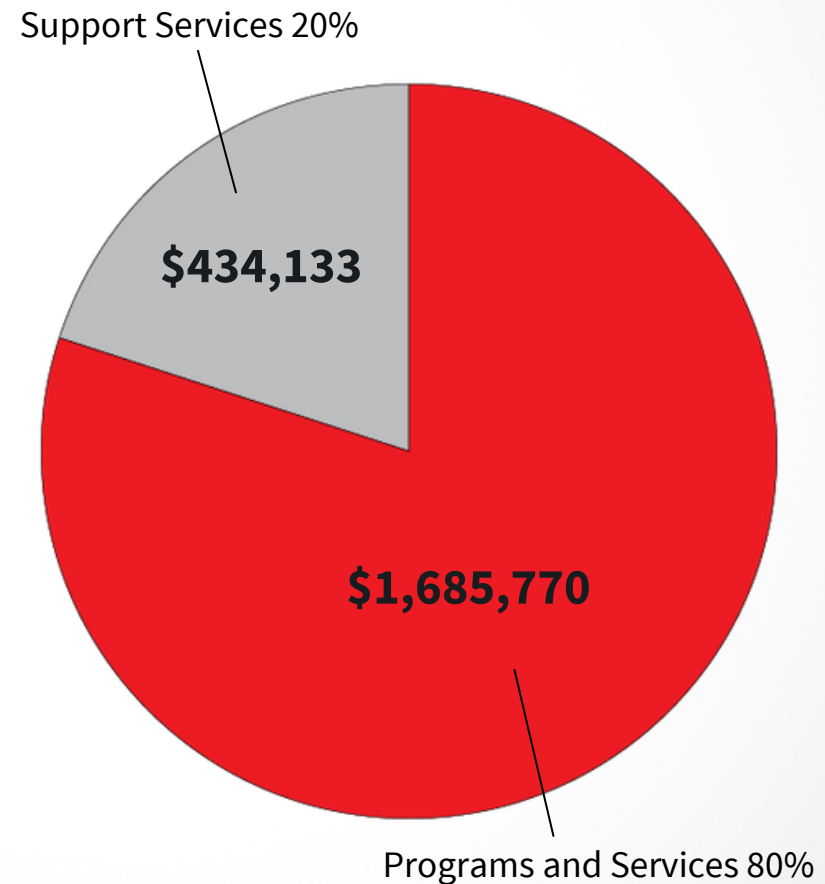
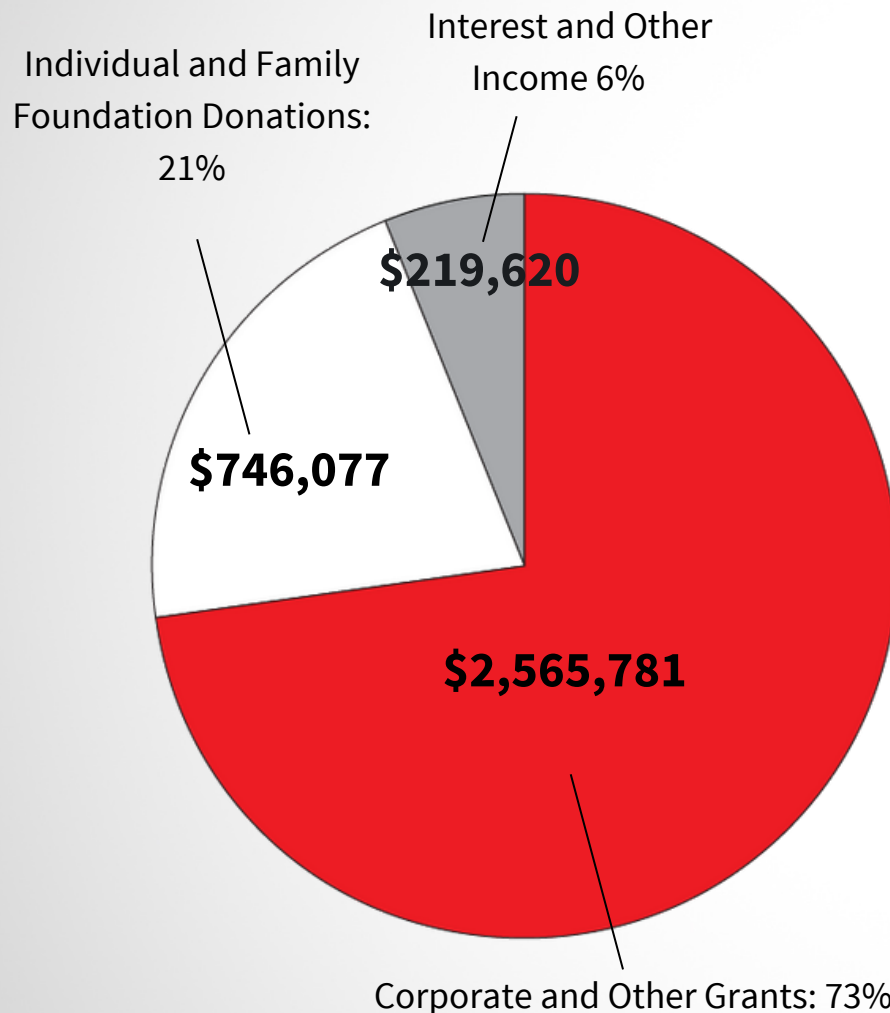
**Your support helps fund research for  
improved treatments until cures are  
discovered!**



AAMDSIF carefully stewards the donations we receive from supporters like you. We are committed to investing your contributions efficiently and effectively.

## 2021 Audited Financials

## 2021 Audited Revenue



*AAMDSIF is a 501(c)(3) nonprofit charitable organization that raises our annual operating budget from individuals, fundraising events, corporations and private foundations. 80% of our support is dedicated to providing education, information, and research.*

# Corporate and Foundation Sponsors

Thank you for your partnership in this important work.



## Patient Education Council

The AAMDSIF Patient Education Council was created in 2008 to serve as a resource to the AAMDSIF staff in the development and review of patient education materials, programs, and services.

Members of the PEC include doctors, nurses, patient educators, patients and caregivers, all of whom have an interest in supporting the needs of people living with aplastic anemia, MDS, PNH or another bone marrow failure disease.

### Chair

Isabel Schuermeyer, MD

### **Members**

Taylor Buss, MSW

Tom Clark

Ellen Coneybear

Paige Cranwell

Robert Delfeld

Ron Duncan

Brandi Lewis

Benton Bergman

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Sandrine Niyongere, MD

Joan Powell

Saira Sufi

Olga Rios, R.N.

Barbara Weinstein, BSN

Lydia Siders

## Patient and Educational Partners

AAMDSIF works with academic medical institutions, patient and professional organizations, and medical education providers to offer educational programs, resources, and support.

**American Association of Nurse Practitioners**

**American Society of Hematology**

**Be The Match**

**BMT InfoNet**

**Cedars-Sinai Medical Center**

**Cleveland Clinic Taussig Cancer Institute**

**Fanconi Anemia Research Fund**

**Fred Hutchinson Cancer Research Center**

**GRYT Health**

**HealthWell Foundation**

**HMP Education**

**i3 Health**

**Imedex**

**Karmanos Cancer Center**

**Leukemia & Lymphoma Society**

**Maddie Riewoldt's Vision**

**MDS Alliance**

**Medical Learning Institute**

**National Comprehensive Cancer  
(NCCN)**

**National Organization of Rare  
Diseases (NORD)**

**Oncology Nursing Society**

**Patient Access Network  
Foundation**

**Patient Advocate Foundation**

**PlatformQ Health**

**PNH Global Alliance**

**The Assistance Fund**



## AAMDSIF Board of Directors

AAMDSIF is fortunate to have dedicated, qualified professionals on our Board of Directors who believe deeply in our mission.

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**Richard Stone, MD**

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**Neal Young, MD**

National Heart, Lung, and Blood Institute

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<b>Manager, Health Professional Programs &amp; Research</b>	Sofia Semanaz
<b>Director of Patient Services</b>	Leigh Clark
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<b>Senior Director of Development</b>	Desiree Ruiters
<b>Development Associate</b>	Elise Harper



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