CONTENTS

MOTIVATION....1   FINANCIALS......11
MISSION..........3   SUPPORTERS...12
IMPACT..........5   LEADERSHIP.....15
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

In 2021, 871 individuals participated in one of AAMDSIF’s support groups.
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)
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:

- Nearly 100,000 views of content on YouTube!
- 1,244,228 unique website visitors
- Top 10 countries: United States, India, United Kingdom, Canada, Australia, Philippines, France, Nigeria, Italy, Brazil
- 2,943 webinar participants
- 7,430 digital patient education publications downloaded
- 423 new patient packets mailed
- 86 peer support network volunteers
- 67 support group meetings
- 5 virtual patient & family conferences

You can watch past webinar recordings here (aamds.org/education/webinars)
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
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.
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.
AAMDSIF carefully stewards the donations we receive from supporters like you. We are committed to investing your contributions efficiently and effectively.

2021 Audited Financials

- Individual and Family Foundation Donations: 21%
- Corporate and Other Grants: 73%
- Interest and Other Income: 6%

$2,565,781

2021 Audited Revenue

- Programs and Services: 80%
- Support Services: 20%

$1,685,770

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.

<table>
<thead>
<tr>
<th>Abbvie</th>
<th>Acceleron Pharma</th>
<th>Agios</th>
<th>Alexion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apellis</td>
<td>Ascenage Pharma</td>
<td>Beatrice &amp; Leon Friedman Foundation</td>
<td>BioCryst</td>
</tr>
<tr>
<td>Bristol Myers Squibb</td>
<td>Charles &amp; Marion Weber Foundation</td>
<td>Edward and Bethel Kean Charitable Foundation</td>
<td>Edward Irvin Fund</td>
</tr>
<tr>
<td>Herman Goldman Foundation</td>
<td>Genentech</td>
<td>Geron</td>
<td>The Henry &amp; Marilyn Taub Foundation</td>
</tr>
<tr>
<td>Incyte</td>
<td>Janie Dean Charitable Foundation</td>
<td>James A Reep Family Foundation</td>
<td></td>
</tr>
<tr>
<td>Jazz Pharmaceuticals</td>
<td>Kenney Family Foundation</td>
<td>Mark and Glynn Snow Family Foundation</td>
<td></td>
</tr>
<tr>
<td>Novartis</td>
<td>Pan Foundation</td>
<td>Smart &amp; Final Charitable Foundation</td>
<td>Syros</td>
</tr>
<tr>
<td>Taiho Oncology</td>
<td>Takeda Oncology</td>
<td>The Amy Beck Charitable Foundation</td>
<td>Tito's Handmade Vodka</td>
</tr>
</tbody>
</table>
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
Korey Yamagata
Mario Riveria
Inga Hoffman Zhang, MD, PhD
Joanna Myers Casale, RD, CSO
Ryotaro Nakamura, MD
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.

Kevin Lyons-Tarr, Chair

Harsha Murthy, Vice-Chair and Secretary

Anthony Sanfilippo, Treasurer

Janice Frey-Angel, Chief Executive Officer

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

David Araten, MD
NYU Hematology Associates

Pamela S. Becker, MD, PhD
City of Hope

Carlos M. DeCastro, III, MD
Duke University Medical Center

H. Joachim Deeg, MD
Fred Hutchinson Cancer Research Center

Amy E. DeZern, MD, MHS
Kimmel Cancer Center at Johns Hopkins

Benjamin L. Ebert, MD, PhD
Dana-Farber Cancer Institute

Guillermo Garcia-Manero, MD
The University of Texas MD Anderson Cancer Center

Aristoteles Giagounidis, MD
Marienhospital Dusseldorf, Germany

Deborah Ziff Cook

Rebecca Doane

Bart Fisher

James Gajewski, M.D.

Stephanie Dillon Hamm

Melanie Marquez

Judy Paulette

Saira Sufi

Medical Advisory Board

Chairperson
Mikkael A. Sekeres, MD, MS
Sylvester Comprehensive Cancer Center, University of Miami

Vice-Chairperson
Olatoyosi Odenike, MD
The University of Chicago

Members

David Araten, MD
NYU Hematology Associates

Pamela S. Becker, MD, PhD
City of Hope

Carlos M. DeCastro, III, MD
Duke University Medical Center

H. Joachim Deeg, MD
Fred Hutchinson Cancer Research Center

Amy E. DeZern, MD, MHS
Kimmel Cancer Center at Johns Hopkins

Benjamin L. Ebert, MD, PhD
Dana-Farber Cancer Institute

Guillermo Garcia-Manero, MD
The University of Texas MD Anderson Cancer Center

Aristoteles Giagounidis, MD
Marienhospital Dusseldorf, Germany

Steven Gore, MD
National Institutes of Health

Timothy Graubert, MD
Harvard Medical School
Massachusetts General Hospital Cancer Center

Rami Komrokji, MD
University of South Florida College of Medicine

John Letterio, MD
Case Western Reserve School of Medicine

Jaroslaw P. Maciejewski, MD, PhD
The Cleveland Clinic Taussig Cancer Institute

David Margolis, MD
Medical College of Wisconsin

Kinuko Mitani, MD, PhD
Dokkyo Medical University School of Medicine, Japan

Stephen D. Nimer, MD
Sylvester Comprehensive Cancer Center
University of Miami

Ronald Paquette, MD
Cedars-Sinai

Uwe Platzbecker, MD
Universitätsklinikum Leipzig, Germany

Gail J. Roboz, MD
Weill Medical College of Cornell University

Valeria Santini, MD
University of Florence, Italy

Phil Scheinberg, MD
Hospital A Beneficencia Sao Paulo, Brazil

B. Douglas Smith, MD
Kimmel Cancer Center at Johns Hopkins

Richard Stone, MD
Dana-Farber Cancer Institute

Neal Young, MD
National Heart, Lung, and Blood Institute
2021 AAMDSIF Staff

Chief Executive Officer: Janice Frey-Angel
Communications Manager: Tricia Maddrey Baker
Senior Director of Patient and Health Professional Services: Alice Houk
Manager, Health Professional Programs & Research: Sofia Semanaz
Director of Patient Services: Leigh Clark
Marketing Coordinator: Derek Admana
Senior Director of Development: Desiree Ruiters
Development Associate: Elise Harper

www.facebook.com/aamds
@aamdsif
www.youtube.com/AAMDSIF

www.aamds.org
4330 East West Highway Suite 230 Bethesda, MD 20814
help@aamds.org | (800) 747-2820 | (301) 279-7202