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

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

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

We invite you to partner with us in providing programs and services to patients and health professionals. Partnership opportunities are available through program sponsorships, educational grants, exhibits for selected programs, special events, and charitable contributions.

We are committed to using the Foundation’s resources wisely. We take great pride in having received our ninth consecutive 4-star rating by Charity Navigator, as well as the GuideStar gold level designation, which recognize our careful stewardship of the Foundation. Partnerships help us greatly in this endeavor.

Thank you for joining us in this important work.

John Huber
Executive Director
2014 Corporate Partners

AA&MDSIF recognizes supporters year round for their generous contributions to the work of the Foundation. AA&MDSIF gratefully acknowledges the following companies for their contributions in 2014.

**Chairman’s Circle**
- Celgene Corporation
- Alexion Pharmaceuticals
- Amgen, Inc.
- Onconova Therapeutics Inc.
- Novartis Oncology

**Visionaries**
- Incyte Corporation
- Baxter Healthcare Corporation

**Champions**
- CTI BioPharma

**Patrons**
- 4imprint Inc.
- MEI Pharma, Inc.

**Leaders**
- Acceleron Pharmaceuticals

**Exhibit Partners**
- Genoptix Medical Laboratory
- ARIAD Pharmaceuticals
- Onyx Pharmaceuticals
- Pharmacyclics
- Genentech USA, Inc
- Seattle Genetics
- Merck & Company

**Partner Benefits**
AA&MDSIF Program Partners receive recognition in event signage and literature, on the AA&MDSIF website, in print and electronic newsletters, and in the annual report, among others.
Regional Patient and Family Conferences
AA&MDSIF has offered regional full day conferences for patients and families since 2011. Conference participants receive answers from medical experts and support from other patients and caregivers, and they leave with a sense of optimism and hope. Each conference program is held in collaboration with one or more nationally recognized healthcare institutions. Regional conferences also help foster the creation of “Community of Hope” support groups. Live international webcasts of conference sessions were added in 2013. Six conferences will be held in 2015. Webcasts from the conferences are posted on the AA&MDSIF Online Learning Center. There are approximately 125-150 participants at each conference.

Online Learning Center
The AA&MDSIF Online Learning Center provides easy access to presentations by leaders in bone marrow failure diseases. Interactive learning modules are available in English and in Spanish. 2015 content will include:

- Current thinking to help patients and families manage their new normal
- Extended “Frequently Asked Questions” interviews
- Critical patient issues
- The importance of treatment adherence

Webinars
Recorded webinars posted on the AA&MDSIF Online Learning Center bring educational resources to patients and families at their convenience. The 2015 webinar series will provide 30 concentrated, interactive learning experiences with experts in bone marrow failure diseases. AA&MDSIF live webinars offer the opportunity to submit questions in writing or pose “live-voice” questions to interact directly with the presenter(s). More than 100 webinars are archived on the Online Learning Center.

Webcasts
Live webcasts from 2013-14 patient and family conferences enabled participants from across the United States and around the world to be right “in the room” for valuable medical sessions on bone marrow failure diseases. To date, AA&MDSIF has aired 12 webcasts, which are now available through the AA&MDSIF Online Learning Center. Live webcasts will continue to be a critical component of 2015 conferences.

Treatment Tracker
The AA&MDSIF Treatment Tracker is a tool for patients with bone marrow failure diseases to track treatment, document and display in graph form any symptom/side effects experienced, as well as create a record and monitor lab results. Instructional videos for patients and health professionals will be created in 2015 to support understanding smart phone/tablet Treatment Tracker information and utilizing the Tracker to enhance communication with physicians.

Research Updates for Patients
Written summaries and interviews provide easy access to high quality and significant research on bone marrow failure diseases, their treatment, and supportive care modalities. 2015 Research Updates for Patients will provide patients and families with the most up-to-date information about significant research in bone marrow failure disease diagnosis, prognosis, and treatment presented at ASH 2014 and at ASCO and EHA in 2015. Patient focused reports will be presented in:

- Two 60-minute live webinars then archived in the AA&MDSIF Online Learning Center.
- Two plain language written summaries available at www.AA&MDS.org and in print.
- Commentary with 5-7 of the principle investigators
Standing Up for Your Health: Rare Diseases

AA&MDSIF developed Standing Up For Your Health to help people with bone marrow failure diseases become effective self-advocates and better navigate the healthcare system. In an eBook format, Standing Up for Your Health 2015 will:

• Address the challenges faced by patients and families facing all rare diseases
• Help caregivers become more effective advocates for their loved ones
• Provide information for parents of young children with rare diseases
• Address the needs of teenagers and young adults who are learning to self-advocate, but still need support from parents or others
• Help adult children advocate on behalf of senior patients

Newsletters and Guides

The twice monthly e-newsletter covers AA&MDSIF programs, outside events, and information of interest to patients and families.

The Research Connection, published monthly, presents information and interviews from leading medical researchers, stories from patients who have been affected by research, and highlights of the research in lay language that AA&MDSIF supports through generous contributions.

The Aplastic Anemia Connection, published quarterly, provides information and support on aspects of treating, managing, and living well with aplastic anemia.

The PNH Connection, published quarterly, provides information and support on aspects of treating, managing, and living well with paroxysmal nocturnal hemoglobinuria.

Patient Education Materials

Packets with disease-specific basic guides, booklets on living well with bone marrow failure disease, and informational fact sheets are mailed free of charge to all patients and families, health professionals and the media.

Supporting Students with Bone Marrow Failure Diseases provides basic information about bone marrow failure diseases and their symptoms, along with tips for teachers and school personnel about how to best support students with a bone marrow failure diseases in the school environment.
Health Professional Education and Resources

ASH Satellite Symposium
AA&MDSIF will once again collaborate with the Cleveland Clinic Educational Foundation to present a Satellite Symposium on the Friday preceding the 57th American Society of Hematology (ASH) Annual Meeting in 2015. The program features internationally recognized faculty presenting the latest research addressing the diagnosis, prognosis, and treatment of bone marrow failure diseases. The program attracts several hundred participants and the recorded program is viewed by many more through the AA&MDSIF website and the Cleveland Clinic Educational Foundation web portal.

International Bone Marrow Failure Disease Scientific Symposium 2016
Every two years, AA&MDSIF brings together experts from around the world who are treating patients with bone marrow failure diseases or studying the immunology and cell biology of these diseases. Experts join with young investigators to learn about the key areas of current research and to explore the most promising directions for the future. The 2016 International Bone Marrow Failure Disease Scientific Symposium will provide recommendations for future laboratory and clinical research focus, clinical trials to advance the standard of care, and promising collaborative translational research opportunities.

Nursing Education Programs and Resources
AA&MDSIF offers continuing education programs and resources for nurses. Programs in 2015 include:

- Satellite Symposium at the 2015 Oncology Nursing Society (ONS) Congress focusing on current perspectives of MDS, including disease biology, diagnostic evaluation, and treatment options for low-risk and high-risk MDS, and the nurse’s role in managing treatment and educating patients and caregivers. The program will be recorded and made available on the AA&MDSIF website.
- In-service modules and research updates on bone marrow failure diseases

Outreach to Community Hematologists/Oncologists
The Treating MDS Toolkit and the MDS Risk Classification Mobile App and iPad version are among the resources AA&MDSIF provides for community hematologists/oncologists for the benefit of their patients. Risk calculators from the mobile app are also available on the AA&MDSIF website. The “What Is MDS?” iPad app is a resource for both clinicians and patients.

New and enhanced resources in 2015 will include:
- Counseling tools for healthcare professionals and updated patient education materials
- Surveys of MDS patients and physicians and nurses who treat MDS
- Webcasts on core issues of bone marrow failure disease
- Commentaries and opinion articles submitted to professional journals
- Toolkits for aplastic anemia and PNH.
- A peer-to-peer physician program with AA&MDSIF-designated experts
- Expanded social media targeting healthcare professionals
- Updates to the mobile app
- Interactive e-book of resources for health professionals

Webinars and Webcasts
Webinars feature key opinion leaders in bone marrow failure disease providing a roundtable update on significant developments from annual professional meetings. Continuing medical education credit will be offered for participation. Topics include:

- New strategies for diagnosing and classifying bone marrow failure diseases
- Advances treatments and new protocols for therapy
- Clinical trial updates
- Diagnostic and treatment overlap with other myeloproliferative neoplasms
Electronic Newsletter
The e-newsletter for Health Professionals is distributed quarterly to more than 30,000 physicians, nurses, researchers, social workers, and other health professionals who work with patients with bone marrow failure disease. Articles include:

- Practical treatment guidance, communicating with patients, and applying research findings written by AA&MDSIF Medical Advisory Board members and other experts
- Research updates
- Information on patient education resources and techniques
- Continuing Medical Education (CME) opportunities

Research Grants
For more than 25 years, AA&MDSIF has provided financial support for research to advance the understanding and treatment of aplastic anemia, MDS, and PNH. Researchers are invited to apply for two-year grants of $30,000 per year to test new ideas and to explore other research leads.

To date, AA&MDSIF has awarded $4 million in research grants to 60 grantees for 68 research projects.

Summer Research Fellowships
The AA&MDSIF Summer Fellowship Program fosters an interest among students in the areas of basic, clinical, and translational research relevant to aplastic anemia, MDS, PNH, and other related bone marrow failure diseases with grants of $5,000.

I always refer my patients to AA&MDSIF with a great deal of confidence, because I know they'll receive reliable, unbiased information in a format that is digestible, and wonderful support from people who know what they're going through.

Mikkael Sekeres, MD, MS
Cleveland Clinic Taussig Cancer Center
Communities of Hope

Communities of Hope are volunteer led local groups to support patients and families with bone marrow failure disease and to raise awareness and support for the AA&MDSIF programs. The members themselves create the community to support their needs, and each group functions in their own way – all with the help and support of AA&MDSIF. These groups function as:

- A patient support group: Members connect to discuss issues that are important to them and to share experiences.
- An enhanced support group: Healthcare or other community professionals may speak at group meetings, and the members may partner with a local health facility for additional resources and information.
- A Fundraising/Awareness group: These groups hold a specific events or activities.

AA&MDSIF currently has 17 Communities of Hope with 6 more in development.

Social Media Outreach

Through social media, AA&MDSIF integrates conferences, meetings, events, and significant advances in bone marrow failure diseases to inform patients and families, clinicians and researchers, as well as to grow domestic and international audiences. Digital media tools allow AA&MDSIF to reach bone marrow failure disease patients anytime and anywhere.

In 2015, AA&MDSIF will:

- Strengthen the AA&MDSIF YouTube channel with short clips from all Online Learning Center content to promote more viral dissemination of content. Add patient stories at conferences and meetings and ask for short videos to create a library on the AA&MDSIF YouTube channel.
- Continue to expand the use of both current and emerging social media venues and technologies to engage and increase awareness of bone marrow failure disease and services available to multiple audiences, stakeholder groups, and constituencies, both in the U.S. and abroad.
- Enhance the customization of the Online Learning Center by creating the ability to share content and opinions via social media.
- Explore appropriate technology for creating more opportunities for connections – telephone, chat, electronic.
- Utilize current, new, and emerging technologies to link patients and families with their counterparts through the peer-to-peer Support Connection, support groups, and other linkages.
- Share content with healthcare providers via Twitter to further reach patients and families.
- Generate social media activity with contests (photo sharing, medical facts, items learned)

Support Connection

The AA&MDSIF Support Connection is a national network of patients, caregivers, and family members who volunteer to share personal experiences, coping strategies, problem solving skills, and other resources. One-to-one sessions take place over the phone and via email. The program will be enhanced in 2015 with:

- An interactive training module for volunteers
- A volunteer and participant recognition program
- A quarterly electronic newsletter
- A standardized questionnaire to monitor activity with volunteers and participants, evaluate efficacy and monitor progress

Scholarship Program

AA&MDSIF provides scholarships to support young people who, in fighting diseases like aplastic anemia, MDS, or PNH, may have had to interrupt their studies, and whose families find it financially difficult to afford higher education. Awards range from $1,000 - $2,000 per student per year.
MDS Global Awareness Program

Working with existing patient advocacy organizations in Europe, Canada, the United States, and Australia, AA&MDSIF shares educational materials and programs, adapting and translating them for use in other countries, and assists program partners in developing their organizational capacity.

MDS Alliance

AA&MDSIF serves as the first convener and the administrative secretariat of a new organization focusing on the common experience of living with MDS as a patient and on serving that population as an advocacy community.

MDS Alliance members include: (USA) Aplastic Anemia & MDS International Foundation, (USA) MDS Foundation, (Canada) Aplastic Anemia & Myelodysplasia Association of Canada, (Spain) Asociación Linfoma Mieloma y Leucemia, (Germany) Leukämiehilfe Rhein-Main-MDS, and (Great Britain) MDS-UK. Membership will be expanded to include additional patient organizations, professional organizations, and institutional affiliates. A leadership group from patient advocacy groups representing the US, Canada, Germany, Great Britain, and Spain provides guidance and governance.

Program activities in 2015 include:

- Building organizational capacity for developing member groups
- Generating awareness about the MDS Alliance in the global hematology community
- Launching a website in multiple languages
- Developing diagnostic and treatment updates for general practitioners and gerontologists
- Advocating on behalf of MDS patients worldwide

Having both of my senior parents diagnosed with bone marrow failure disease, I attended the AAMDSIF conference with a mission in my heart—seeking understanding of this disease, how it progresses, and all of the possible treatments. I left that day with all of those questions answered. The unexpected gift that day: I found just the right blend of encouragement, expert information, personal stories, and an opportunity for on-going connections and help.

- Jennifer

“
Special events held across the United States raise funds, friends and awareness.

National Hope, Steps & A Cure Walk Sponsorship
- Funding will provide: t-shirts for participants and volunteers; printing of banners, signs, programs; bags for participants; hats for committee members; gift for child participants; printing and postage for promotional postcards; advertising costs for Facebook promotions
- Sponsor receives: name/logo on AA&MDSIF website, walk registration site, banner/signage at walk, t-shirt, all collateral, program, and AA&MDSIF conference volunteer PowerPoint presentation; tabling opportunities at walks; sponsorship announced to all participants at all walks

Individual Hope, Steps & A Cure Walk Sponsorship
- Funding will provide: t-shirts for participants and volunteers; bags for participants; printing of banners, signs, programs; refreshments for participants; advertising costs for Facebook promotions
- Sponsor receives: name/logo on walk registration site, t-shirt, all collateral, posters/signs, program; tabling opportunity at walk

National Event Sponsorship
- Funding will provide: bags for event participants; printing of banners, signs, programs; printing and postage for promotional postcards; design and printing of promotional national flyer; refreshments
- Sponsor receives: name/logo on AA&MDSIF website, marketing materials, posters, program, AA&MDSIF conference volunteer PowerPoint presentation

Awareness Week Sponsorship
- Funding will provide: awareness kits for volunteers and postage; magnets; printing for promotion/marketing; postage; advertising costs for Facebook promotions
- Sponsor receives: name/logo on AA&MDSIF website, marketing materials, posters, program, AA&MDSIF conference volunteer PowerPoint presentation

Community of Hope Sponsorship
- Funding will provide: printing for national promotion/marketing; postage; advertising costs for Facebook promotions; advertising costs for local promotion; magnets; pens/paper for meetings
- Sponsor receives: name/logo on AA&MDSIF website, AA&MDSIF conference volunteer PowerPoint presentation, Community of Hope flyers

“Volunteering our time, spreading awareness, holding bone marrow drives, participating in the Hope, Steps & A Cure Walk, and fundraising on behalf of AA&MDSIF is the most important way we can give back to this wonderful foundation. I happily participate in contributing my time to the foundation so that they can continue to provide programs and services, hope and support to other patients and families, just like ours.”

- Patient/volunteer
As a patient, one of the first thoughts that comes to mind when I think of support for my bone marrow failure issues is AA&MDSIF. When it seemed there were no answers, and little hope, the Foundation provided plenty of both at the three Patient Conferences I’ve attended, and during the many webinars I have heard. I always learned something new from the many excellent speakers and made many friends, who offered both support and hope as we all learned how to cope, and move forward. I’ve especially learned that we can’t do it alone. While it sounds like a slogan, ‘Answers, Support, and Hope’ are what the Foundation is all about.

- Gloria