This report represents Aplastic Anemia & MDS International Foundation Inc's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

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Mission:
The Aplastic Anemia & MDS International Foundation (AA&MDSIF) fights bone marrow failure diseases through patient support and research which provide answers, support and hope.
The content of this Charting Impact Report is the sole product and responsibility of Aplastic Anemia & MDS International Foundation Inc. This report does not in any way represent an endorsement from Independent Sector, BBB Wise Giving Alliance, or GuideStar, nor does it represent fulfillment of the BBB Wise Giving Alliance’s *Standards for Charity Accountability*. For more information on Charting Impact, visit [www.guidestar.org/chartingimpact](http://www.guidestar.org/chartingimpact)
1. What are we aiming to accomplish?

As 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, the Aplastic Anemia & MDS International Foundation strives to be the resource of choice throughout the three phases of bone marrow failure diseases. These include diagnosis, treatment, and living with a chronic disease. To accomplish this, AA&MDSIF organizational priorities include enhancing patient and health professional education, supporting research, increasing public awareness and advocacy, and providing patient and family support.

2. What are our strategies for making this happen?

Goal 1: Increase awareness of bone marrow failure diseases among health providers at all levels in order to accelerate time-to-diagnosis and treatment, to improve clinical outcomes, and to enhance the care experience. Goal 2: Fully establish the Foundation as the “resource of choice” related to bone marrow failure diseases for patients, family members, and caregivers. Goal 3: Promote, fund, and administer promising basic, clinical, and translational research initiatives with the longer term goal of finding cures for bone marrow failure diseases. Goal 4: Build expanded awareness and understanding of bone marrow failure diseases among the public-at-large in the U.S. and overseas. Goal 5: Develop and sustain diverse and accessible support networks and services for patients, family members, and/or caregivers. Goal 6: Join with other advocacy organizations to identify and pursue selected legislative and regulatory issues and opportunities at the federal and state level that advance or affect research, treatment, and reimbursement related to bone marrow failure diseases or other rare disorders. Goal 7: Secure the resources necessary and take additional steps to ensure that the Foundation is a growing, sustainable, effective, and productive organization that can satisfy patient/stakeholder needs.

3. What are our organization’s capabilities for doing this?

Established in 1983, the Aplastic Anemia & MDS International Foundation (AA&MDSIF) currently has 16 employees, (11 full-time and five part-time) and receives assistance from approximately 700 volunteers throughout the United States. The Board of Directors provides financial and strategic oversight and is comprised of 12 community and business leaders from across the country, each of whom has a connection to bone marrow failure disease. AA&MDSIF’s Medical Advisory Board (MAB) includes experts in aplastic anemia, MDS, PNH, and bone marrow failure diseases from the nation’s leading medical and research institutions. The 23-member MAB advises and provides professional and technical expertise to the AA&MDSIF board and staff on medical, clinical and scientific matters. In addition, the MAB is responsible for the peer review of research grant applications and recommendations for funding. A 25-member Patient Education Council serves as a resource in the development and review of patient education programs and materials. AA&MDSIF collaborates with related organizations, and shares information about bone marrow failure diseases for both patients and healthcare professionals with other health organizations. AA&MDSIF Regional Patient and Family Conferences are held in partnership with leading clinical centers, including The Mayo Clinic, The Cleveland Clinic, Dana-Farber, and Weill-Cornell Medical Center. The MDS Clinical Research Consortium is a critical partnership with six of the leading medical centers treating MDS patients in the U.S. AA&MDSIF receives support through individual contributions from patients, families, and friends, as well as through foundations and corporations. AA&MDSIF has received Charity Navigator’s four-star rating for nine consecutive years, achieved by only the top 1% of charities in the United States.

4. How will we know if we're making progress?

AA&MDSIF conducts surveys on the impact and effectiveness of its publications and webinars. AA&MDSIF tracks the (1) number of documents requested by mail, (2) the number of visits and documents downloaded from the website, (3) and
collects any comments that are sent to us by email or regular mail. Anecdotal feedback is also obtained via social media and when documents are distributed at patient and family conferences.

5. What have and haven't we accomplished so far?

Serving patients and families experiencing bone marrow failure disease worldwide, AA&MDSIF achieves its mission through programs and services which include: Personalized support from a patient navigator. A Support Connection network matches patients and caregivers looking for peer support. A website, AAMDS.org, which acts as a primary information source on treatment, research, services, and patient stories—more than 250,000 unique visitors in 2013, along with nearly 5,000 Facebook fans and almost 500 Twitter followers. An Online Learning Center featuring free webinars, webcasts, interactive learning modules and interviews with leading medical experts—4,200 registrants for 33 webinars in the past two years. Smartphone, IPad apps, and treatment tracker tools are also available. More than 100 webinars are archived. Free regional patient and family conferences—More than 3,200 registrants for 26 conferences held over the last four years. Local community support groups meeting throughout the country, known as Communities of Hope, enable patients and families to connect with each other, share information, and raise awareness in their communities. 20 Communities nationwide to date. Funding of medical research—since 1989, grants totaling more than $3.8 million have been awarded to 67 researchers. Educational programs for health professionals. Scholarships for students impacted by bone-marrow failure disease—73 totaling $111,00 awarded since 2008. Free patient and healthcare provider information packets sent within 48 hours of request. Publications that include medical research summaries and a family of online and print publications. Print newsletters are distributed to more than 33,000 individual households and a health provider list of 10,000. Email newsletters are sent to 35,000 subscribers. These include monthly research updates, general newsletters, and targeted communications about conferences, webinars, and other programs and services. The MDS Clinical Research Consortium—Launched in 2012, the award-winning consortium is a collaboration of six leading medical centers to advance treatments and improve outcomes for MDS patients. Each of the participating medical centers serves a high volume of MDS patients, and is home to the leading MDS specialists and researchers. The five-year, $16 million program is sponsored by AA&MDSIF and supported by the Edward P. Evans Foundation.