



## **BACKGROUND/MISSION**

Founded in 1983, the Aplastic Anemia & MDS International Foundation (AA&MDSIF or the “Foundation”) 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 diseases:

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

AA&MDSIF fulfills this mission through a comprehensive range of activities including:

- Free, personalized support from patient educators.
- Developing and distributing a wide range of disease-specific educational materials and content including, websites, print materials, patient and family conferences, a comprehensive online learning center, peer support network and Communities of Hope.
- Funding medical research to advance the understanding and treatment of Bone Marrow Failure Diseases. Thanks to the generosity of those who support the Foundation, AA&MDSIF has awarded more than \$5 million in research grants.
- AAMDSIF maintains and promotes a global patient registry for PNH patients which gathers information from patients about their experience with the disease and will allow them access to this collective information.
- Providing patients and health care providers the most up-to-date information about bone marrow failure diseases, their diagnosis and treatment.
- Raising public awareness about Bone Marrow Failure diseases.

AA&MDSIF has an annual operating budget of \$3 million, with a professional staff of ten. It has received Charity Navigator's highest 4-star ranking for ten consecutive years.

The Foundation is in Bethesda, Maryland. We are presently conducting operations in a hybrid format.

The Foundation is guided by a national board of directors composed of 11-15 members. The Board is composed of former and current patients, business executives, lawyers, and physicians. The Board meets quarterly with 1-2 in-person meetings per year.

## **THE OPPORTUNITY**

AA&MDSIF seeks a highly qualified, innovative, and motivated leader who can build upon the Foundation's successful track record and strong reputation.

### **Primary Responsibilities:**

#### Strategic Leadership:

- Collaborate with the Board of Directors to develop, refine, implement, and measure progress on the current and subsequent strategic plans and initiatives.
- Serve as a passionate and engaged Ambassador, articulating and communicating the Foundation's vision and mission to a wide range of audiences and stakeholders.
- Identify and leverage emerging opportunities to deepen the organization's impact, broaden its reach and strengthen and diversify its funding.

#### Organizational Management:

- Maintain a culture of excellence based on honesty, integrity, transparency, and accountability. Oversee the day-to-day operations of the Foundation and programs in such a way as to ensure that AA&MDSIF maintains and builds on its reputation as a well-managed, effective, and respected organization.
- Lead the Foundation and staff in keeping with the Foundation's Code of Ethics and internal policies. Ensures that the Foundation operates ethically and legally in all its dealings and maintains appropriate confidentiality.
- Develop and lead the Foundation staff, setting positive and clear expectations and objectives and providing opportunities for growth and development. Manage direct reports and outsourced accounting staff.
- Direct the ongoing development of an organizational structure and associated procedures that support the current needs of the Foundation and provide capacity for continued growth.
- Develop an appropriate annual operating plan and budget for presentation and approval by the Board and oversee its successful implementation. Maintain a continuous understanding of the Foundation's financial position and outlook and commit to working to secure its financial future.
- Ensures that the Foundation operates in a fiscally responsible manner, including proper internal controls, sound cost management practices, timely completion of the audit including any corrective action arising, and timely completion and filing of the form 990.

- Supports the Board of Directors in its governance role and fosters its ongoing development. Keeps the Board fully informed on the operation of the Foundation and important external developments. Serves as a non-voting, ex-officio member.

#### Development/Fundraising:

- Provide the vision and direction necessary to develop a thorough and fully diversified funding strategy that enables the Foundation to deliver on its mission now and in the future. Such a plan includes establishing clear goals (and tracking progress against them) and continuously identifying ways to secure new and increased funding sources. It also optimizes the available assets and skills of board members, staff, volunteers, medical advisory board members and other stakeholders.
- Lead the fundraising and development efforts, particularly in the area of developing strong relationships with key donors and corporate partners.
- Be fully aware of and utilize emerging new technologies and strategies in service of fundraising and communications.

#### Programs and Services to Patients and Families:

- Provide the vision and direction necessary to maintain and continuously improve a robust, respected and sought after offering of educational materials, content, tools and support services to patients and families.
- Be fully aware of and utilize emerging new technologies and strategies for communication and delivery of the Foundation's materials and services.
- Act as primary liaison with other bone marrow failure organizations around the world to best serve patients and families.

#### Communication with the Medical Community:

- Provide the vision and direction necessary to maintain and continuously improve a robust, respected and sought after offering of educational materials, content and tools geared towards the medical community to help raise awareness of Bone Marrow Failure diseases.
- Work with the Medical Advisory Board to obtain and vet information, increase advocacy, and promote research.
- Act as the primary liaison to the medical and research community, building strong relationships with the Foundation.

#### Research:

- Work with all appropriate stakeholders to identify and develop research strategy and identify opportunities.
- Maintain up-to-date information on the pharmaceutical industry and current and emerging treatment options and clinical studies.

#### Advocacy and Awareness:

- Serve as the Foundation's ambassador and 'educator in chief,' effectively communicating the organization's mission to a variety of constituencies.
- Serve as persuasive representative for patients and mission promoting bone marrow failure disease issues to governmental bodies.
- Maintain up-to-date information on pending legislation with potential impact on bone marrow failure research issues that may affect patients and families and/or the ability of the Foundation to carry out its mission.
- Promote and execute government relations/advocacy plans to support organizational objectives and priorities.

#### **QUALIFICATIONS:**

- Significant track record of exceptional executive leadership, strategic planning, and performance excellence in a multi-faceted non-profit organization.
- A background or experience in health services or patient support is not required but is preferred.
- A leadership philosophy that embraces open communication, transparency, collaboration, and accountability operating in an environment of honesty and highest integrity.
- A deep sense of compassion and empathy for the full range of issues patients and families face in dealing with serious medical conditions like Aplastic Anemia, MDS, PNH and other bone marrow failure diseases with a passion for making a positive difference in their lives.
- Excellent communication skills with the proven ability to successfully act as the primary spokesperson for the Foundation. Ability to communicate effectively with a variety of constituencies - including patients, families, doctors, staff, scientists, researchers, funders, government officials, business community and the media - is critical. Must be willing and able to understand, interpret, and translate somewhat complex medical/scientific concepts and information for a range of audiences.
- Demonstrable track record of revenue development success through the development and execution of a fully diversified development strategy
- Proven ability to oversee the development and implementation of a robust and comprehensive support program that includes such as, educational materials, support services, conferences, assessment tools, etc.
- Thorough understanding and experience across a range of applicable business and financial management issues/topics including human resources, organizational culture and effectiveness, resource allocation, and finance.
- Track record of building and maintain strong, effective working relationships with a Board of Directors.
- College graduate: graduate degree desirable but not required.

**For consideration as a candidate to suggest a prospective candidate, please contact in confidence The McCormick Group at: [aamdsif@tmg-dc.com](mailto:aamdsif@tmg-dc.com)**