



**PRESIDENT AND CHIEF EXECUTIVE OFFICER
HEMOPHILIA FEDERATION OF AMERICA**

Location – Remote

[Hemophilia Federation of America](#)



The Aspen Leadership Group is proud to partner with Hemophilia Federation of America in the search for a President and Chief Executive Officer.

The President and Chief Executive Officer will work in collaboration with the Board of Directors on strategy development and provide overall strategic leadership and managerial responsibility for Hemophilia Federation of America (HFA) as it executes on programs and services that advance the organization's mission. The President and Chief Executive Officer will direct the senior leadership team across the organization to ensure that advocacy, programs and services, research, as well as development, finance, volunteerism, marketing, communications, information technology, human resources, and administration activities are organized for optimal success. The President and Chief Executive Officer will maintain a persistent laser eye toward results that support HFA's vision, mission, and key objectives.

The President and Chief Executive Officer will act as a key advocate and spokesperson for HFA, advancing public dialogue on key issues to the bleeding disorders community with key senior stakeholders in similar agencies and regulatory, government, and industry leadership. The successful candidate will be a leader with a solid work ethic, commitment to lead via servant leadership, and willingness to learn and grow with a changing organization.

Hemophilia Federation of America is a nonprofit 501(c)(3) patient education, services, and advocacy organization serving the rare bleeding disorders community. It is exclusively focused on the bleeding disorders patient and caregiver community. Incorporated in 1994, HFA serves as a community-based organization, committed to championing the needs of families living with chronic, often painful, and debilitating bleeding disorders. It advocates for safe, affordable, and obtainable therapies and health coverage. HFA seeks a better quality of life for all persons with bleeding disorders.

HFA works in conjunction with other national and state organizations on behalf of families living with bleeding disorders. Its officers and staff maintain a highly visible presence, representing the bleeding disorders community on Capitol Hill, and speaking regularly before the Food and Drug Administration, Centers for Disease Control and Prevention, and other key agencies. HFA is committed to community education and provides tools and resources to give the community a voice at state and federal legislatures.

HFA consists of a national organization office and 50 state and local community-based member organizations serving men, women, children, moms, dads, siblings, grandparents, and friends impacted by a bleeding disorder. Additionally, HFA works with many non-affected individuals and organizations, such as healthcare providers, therapy providers, specialty pharmacies, donors, and insurers that play a significant role in the community. HFA programs include a wide range of adult outreach initiatives, as well as broad-based support for families living with hemophilia, von Willebrand disease, and other bleeding disorders.

REPORTING RELATIONSHIPS

The President and Chief Executive Officer will report to the Board of Directors, led by Chair Josh Hemann.

PRINCIPAL OPPORTUNITIES

Hemophilia Federation of America recently celebrated 25 years of serving the bleeding disorders community. We were founded out of the desire to directly impact the lives of those living with bleeding disorders. Over the past decade we have grown exponentially in the services we offer as well as our funding. We are over a 6-million-dollar organization that still receives praise over the family atmosphere at our annual symposium.

As we continue our search for the next President and CEO, HFA is set up well with great staff in place and a supportive Board of Directors. Our previous President and CEO was with HFA for over a decade. We are looking for new leadership and someone to take this excellent organization into the future as we look to assist those with bleeding disorders outside our borders, reach underserved populations of our community, navigate the upcoming excitement of new therapies and honoring our past. We are excited to find our next leader to join this collaborative, fun, and exciting organization.

–Josh Hemann, Chair, Board of Directors

PRIMARY RESPONSIBILITIES

Strategy

The President and Chief Executive Officer will

- ensure that the organization is focused on HFA's vision, mission, and key objectives;
- build and communicate a strategic vision that can be highly supported by the Board of Directors and passionately executed by staff and volunteers;
- create clarity around mission and goals and set strategic direction;
- conduct ongoing strategic thinking, and create and deploy strategic plan and short- and long-term plans; and
- maintain an eye toward growth while meeting ongoing needs.

Fiscal

The President and Chief Executive Officer will

- develop and manage budget, providing ongoing budget oversight while ensuring maximum resource utilization and maintenance of the organization in a positive financial position;
- maintain an eye toward growth to meet the ongoing needs of the community;
- regularly analyze the soundness of the organization's financial structure; and
- identify and participate in fundraising and grant writing efforts.

Board Governance

The President and Chief Executive Officer will

- regularly report to the Board of Directors on HFA's impact across all programs and services; and
- build and maintain Board of Directors relationships, fostering positive and effective board decision making.

Management and Leadership

The President and Chief Executive Officer will

- select and build a strong organizational team of employees and volunteers;
- lead continuous improvement efforts across the organization to optimize reach and efficiencies and create sustainability;
- manage and lead the organization to ensure the people, systems, and infrastructure exist that are necessary to successfully sustain growth of programs and services;
- oversee HFA projects, programs, services, and initiatives;
- manage ongoing professional development of functional area staff;
- ensure staff and membership have an environment of creativity that fosters an open exchange of ideas;
- implement policies and processes to drive organization and manage activities; and
- oversee the timely collection and reporting of qualitative and quantitative measures that illustrate the impact and outcomes/result of HFA's work.

Communication

The President and Chief Executive Officer will

- act as a spokesperson for HFA in the bleeding disorders community and in the general public;
- build a strong sense of community within staff, board, volunteers, and others;
- enable creativity and an open exchange of ideas across HFA and its membership; and
- provide consistent, responsive, and effective internal and external communication.

KEY COLLEAGUES



Josh Hemann
Chair, Board of Directors

Josh Hemann loves bringing his perspective to a national level in order to help further the mission of HFA. His dedication can be seen through his involvement in the hemophilia community. As a father of two daughters with bleeding disorders, he knows the importance of the work and mission of HFA. Josh serves as Managed Care Account Executive at ARJ Infusion Services where he manages accounts on a health plan, PBM and TPA level for ARJ Infusion Services; works to develop new strategic partnerships with brokers, captives, and employers to provide competitive pricing and excellent patient care to their members. Josh

received his Bachelor of Arts in Finance from the University of Northern Iowa.



Tracy Cleghorn
Past Chair, Board of Directors

Tracy Cleghorn has been a dedicated member of Hemophilia Federation of America's board for over a decade. While reflecting on the changes of the organization during that time, she said, "Not only has the organization grown, but the organization has helped me grow. It's pushed me to step out of my comfort zone and in return, I've been a part of so many great things happening in our community." Tracy is motivated by her son and says that even though having a

son with hemophilia wasn't the path she had envisioned her life taking, it's been a blessing. "I am beyond blessed with the person my son has grown into and the people that are a part of my life," she said.



Sharon Meyers
Interim President and Chief Executive Officer

Sharon Meyers brings a wealth of experience to her role as Interim Chief Executive Officer. Sharon has been with HFA for nearly four years, most recently overseeing fundraising, marketing and communications, and information technology. She is a Certified Fund-Raising Executive (CFRE) and holds a Nonprofit Management Executive Certificate from Georgetown University in Washington, D.C. She is currently working on a doctorate in education at the University of Southern California in Organizational Change and Leadership. Additionally, she holds a master's in political science from the University of Southern Mississippi. She has 15 years of healthcare and university nonprofit leadership experience at the local, state, regional and national level. Sharon previously led major organizational change initiatives, multimillion-dollar fundraising campaigns, and served as an interim organizational leader multiple times in her career.



Michelle Burg
Vice President of Operations

Michelle Burg's current role in oversight of the Information Technology, Human Resources, Services and General Operations team members provides the opportunity to work with HFA's cross-functional teams to identify ways to build capacity and leverage resources as HFA strives to serve those in the bleeding disorders community. Prior to her work at HFA, Michelle worked in the financial services and retail industries. Michelle holds a BBA from the University of WI-Eau Claire.

PREFERRED QUALIFICATIONS

Hemophilia Federation of America seeks a President and Chief Executive Officer with

- the proven ability to influence and drive change across a diverse population;
- exceptional written and verbal communication skills, including public speaking skills;
- excellent critical thinking, problem solving, project management, and negotiation skills;
- attention to detail and follow through;
- a positive servant-leader attitude and the ability to lead collaboratively on a high-performance team;
- technology proficiency with systems and software; and
- the ability to navigate between the nonprofit, government, and for-profit sectors.

A bachelor's degree is required for this position. An advanced degree is preferred. At least ten years of successful leadership, management, and fundraising experience is preferred as is prior experience successfully managing a nonprofit. An ability to communicate in Spanish is a plus (but not required).

DIVERSITY, EQUITY, AND INCLUSION

It is the policy and commitment of HFA to provide equal opportunity to all qualified persons without regard to race, age, sex, religion, national origin, marital status, sexual orientation or disability. This policy covers all activities of employment, including but not limited to, recruiting, hiring, placement, promotion, demotion, layoff and termination, pay and participation in HFA sponsored activities.

To attract the best people and maintain extraordinary results and performance from our employees, it is HFA's core belief that its employees must realize a high level of job satisfaction. It accomplishes this by providing its employees with challenging work; training and development; rewards and recognition; encouraging a caring work atmosphere; opportunities for staff feedback; and ongoing performance feedback for employee development.

SALARY & BENEFITS

Hemophilia Federation of America offers a competitive salary and benefits package.

LOCATION

This is a remote position, and the successful candidate may have the option to work remotely from anywhere in the United States. There is a preference for the Washington, D.C. Metropolitan area. The successful candidate will be expected to be onsite in Washington D.C. two to three days per month and travel nationally 40% to 50% of the time.

APPLICATION INSTRUCTIONS

All applications must be accompanied by a résumé and a cover letter. **Cover letters should be responsive to the mission of Hemophilia Federation of America.** Review of applications will begin immediately and continue until the successful candidate has been selected.

To apply for this position, visit:

[*President and Chief Executive Officer, Hemophilia Federation of America.*](#)

To nominate a candidate, please contact Angelique Grant:

[*angelique@aspenleadershipgroup.com.*](mailto:angelique@aspenleadershipgroup.com)

All inquiries will be held in confidence.