



## POSITION SPECIFICATION

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### **Chief Executive Officer**

New York, NY

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**NATIONAL HEMOPHILIA FOUNDATION**

*for all bleeding disorders*

## Chief Executive Officer

<b>REPORTING TO:</b>	Board of Directors
<b>DIRECT REPORTS:</b>	Chief Operating Officer; Chief Financial Officer; Chief External Affairs Officer; Chief Research Officer; Senior Vice President, Medical Programs and Information; Vice President.
<b>LOCATION:</b>	New York, NY

### COMPANY DESCRIPTION

#### NATIONAL HEMOPHILIA FOUNDATION

[www.hemophilia.org](http://www.hemophilia.org)

Since 1948, the National Hemophilia Foundation (NHF) has been dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. NHF has 52 chapters throughout the country, seven of which are under the NHF charter, the others independent 501 (c) (3) organizations. Its programs and initiatives are made possible through the generosity of individuals, corporations and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

Since 1972, NHF has been awarding grants and fellowships to support innovative research aimed at finding better treatments and cures for bleeding disorders. This research has led to vital insights into improved factor replacement therapies, more accurate hemophilia diagnostic methods and a greater understanding of the genetic basis of hemophilia.

Through the efforts and guidance of NHF's Medical and Scientific Advisory Council (MASAC), an internationally renowned group of expert scientists, physicians, and other treatment specialists, NHF has long been engaged in advancing the standard of clinical care and issuing treatment recommendations for all bleeding disorders. In the coming years NHF will increase its approach to research

NHF supports increased federal funding for research. In addition, its public policy agenda includes working for improved access to high-quality medical care, a safe blood supply, access to the full range of safe and effective treatments, adequate reimbursement at the public and private levels, and expanded federal funding for hemophilia treatment centers. Washington Days, NHF's annual national advocacy conference, brings together people from across the country to make their voices heard and influence the legislative process.

Today, NHF seeks to build on its history of success in an effort to even more impactfully serve the community, fulfill its mission and achieve sustainability. Strategic directives include 1) Diversifying funding, 2) Raising its national profile further through marketing and communications efforts and lobbying for federal support 3) Focusing on research, directing increased attention toward finding a cure for inheritable bleeding disorders. The NHF plays an important role internationally as well, providing educational resources through its website and its participation on the international council.

The NHF, headquartered in NYC, has an annual operating budget of approximately \$23 million. Together with its independent network of local and regional chapters, it constitutes an annual turnover in excess of \$60 million.

## SCOPE AND RESPONSIBILITIES

The Chief Executive Officer (CEO), in partnership with the Board of Directors, sets the strategic direction of the organization and directs the senior management team. He/she will evaluate strategic long and short-term opportunities and direct the planning and administration of programs, partnerships, and policy work of National Hemophilia Foundation. As chief spokesperson and fundraiser, the CEO will represent and advocate for the organization with governmental leaders and policy makers and encourage and solicit donors and prospective donors to create the resources required to allow the organization to meet the needs of its constituents. The successful CEO will continue to have a significant positive impact on the individuals in need, their families and communities, and advance the efforts to find a cure for hemophilia.

### Specific Responsibilities:

- As CEO of National Hemophilia Foundation, develops and recommends to the Board of Trustees specific strategic and operating long range plans for the development and implementation of programs, services, and advocacy priorities.
- Represents the organization to its various stakeholders – chapters, funders, partnering agencies, governmental agencies, families, children, and the community.
- Promotes strong governance and builds board capacity, assisting the board in recruiting new board directors as necessary.
- Leads/stewards the organizational culture and values; models mission-focused commitment.
- Ensures the financial sustainability of the organization through sound financial management, business planning, and resource development, particularly major gifts fundraising.
- Supervises and develops talent and leadership capacity of senior management team, evaluates their individual performance, and builds capacity throughout the organization.
- Oversees the evaluation of NHF programs, contextualizes the results, and creates programs in response to the need in the community.
- Develops and maintains relationships with federal agencies, legislators, relevant government employees, and oversees NHF's lobbying efforts.
- Builds brand visibility and value; promotes the blood disorder communities through direct involvement and through public relations programs. Serves as the "public face" of the organization.
- Gives overall direction to, and leads the fundraising activities of National Hemophilia Foundation.
- Maintains appropriate relations with various public/private funding bodies and planning and advocacy organizations.
- Participates in national, state, and local organizations that are compatible with the mission, vision, values and direction of National Hemophilia Foundation.
- Participates in and provides leadership in strategic partnerships and collaborations.
- Stewards and builds assets in service to the mission (financial, talent, facilities).

## KEY SELECTION CRITERIA

The CEO will have leadership experience in not-for-profit medical research and advocacy organizations, with increasing levels of responsibility; or, similar or related experience in other complex, federated social service or philanthropic organizations that deliver services to the public. The successful candidate will be a bold, visionary, entrepreneurial leader capable of guiding a large, traditional organization toward a new business model to achieve new initiatives.

The CEO must have broad knowledge and demonstrated skill in managing health and medical delivery programs, with particular skills in fundraising, marketing and communications, political advocacy, finances, and resource management. Proven skills and a successful track record in leadership, strategic planning, and managing a board is required.

Specifically, the ideal candidate will possess:

- Ten to fifteen years of progressively responsible administrative experience in organizations directly serving individuals, families and children, or in a similar field related to the services provided by National Hemophilia Foundation (highly preferred).
- Proven ability and experience to manage a board and senior leadership to collectively achieve mission-related outcomes.
- Proven ability and desire to engage in fundraising from major donors, foundation, corporations and other sources of contributed income.
- Knowledge of business and management principles involved in strategic planning, resource allocation, leadership technique, production methods, human behavior and performance, and coordination of people and resources. Proficiency in non-profit fiscal and strategic management.
- Proven experience to operate successfully within a complex environment including engaging with federal legislators and governmental agencies, such as the CDC, NIH, and FDA.
- Ability to develop and successfully maintain an extensive network of strategic relationships (donors, politicians, volunteers, community partners, etc.) at the national level and in the markets of the Chapters. Existing network in the blood disorder field a plus.
- An understanding of the health care industries, including the relationships among big pharma, patients and insurers, federal health care insurance, the private insurance markets and hospitals.
- Experience leading through and managing change.
- Demonstrates respect and acceptance of diverse individuals and communities served by, working in partnership with, or employed by National Hemophilia Foundation including but not limited to race, gender, ethnicity, social-economic status, and LGBTQ populations.
- Advanced degree from an accredited program of healthcare education or an advanced degree from an accredited academic program in another, related field of health or social service.

## PERSONAL / PROFESSIONAL ATTRIBUTES

- Demonstrates Inspirational Leadership
- Maintains Strategic Focus
- Fosters Racial Equity, Diversity and Inclusion
- Employs Influential Communication
- Builds Relationships
- Champions Mission of NHF
- Possesses Business/Financial Acumen
- Models Professionalism

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