

Position Specification

President & CEO

September 2023



Formerly NHF
NATIONAL
BLEEDING DISORDERS
FOUNDATION

Innovate | Educate | Advocate



President & CEO

Reporting To	Board of Directors
Direct Reports	Chief Operating Officer; Chief Business Officer; Chief Medical and Scientific Officer; Managing Director, Pathway to Cures
Location	Remote

Company Description

National Bleeding Disorders Foundation

www.hemophilia.org

Since 1948, the National Bleeding Disorders Foundation (NBDF) has been dedicated to finding better treatments and cures for inheritable blood/bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research, so that people and families living with inherited bleeding disorders may thrive. NBDF partners with 50 chapters throughout the country, seven of which are under the NBDF charter, the others independent 501(c)(3) organizations, to deliver programs and offer services which meet the needs of people and families living with inherited bleeding disorders. NBDF's 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). NBDF has a long history of building coalitions and partnerships, working with a number of foundations and organizations, advocacy groups and coalitions for advocacy, access and other public policy needs at the national and state levels.

Through the efforts and guidance of NBDF's Medical and Scientific Advisory Council (MASAC), an internationally renowned group of expert scientists, physicians, and other treatment specialists, NBDF has long been engaged in advancing the standard of clinical care and issuing treatment recommendations for all bleeding disorders.

NBDF's 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, expanded federal funding for hemophilia treatment centers and increased federal funding for research. *Washington Days*, NBDF's annual national advocacy conference, brings together people from across the country to make their voices heard and influence the legislative process.

Since 1972, NBDF has invested more than \$20 million to support innovative research aimed at finding better treatments and cures for blood/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.

In 2020, NBDF began pursuing an aggressive research agenda to hasten the advancement of lifesaving innovations for those with inheritable blood/bleeding disorders. The organization hired its first Chief Scientific and Medical Officer to provide expert oversight of research initiatives. Earlier this year, NBDF launched [Pathway to Cures](#) (P2C), a venture philanthropy fund focused on accelerating the development of cures across all inheritable blood disorders. P2C invests in early-stage companies developing cures, therapies, or enabling technologies to address unmet needs in the inheritable blood disorders community. In addition, NBDF is working to launch a national research network, focused on inherited bleeding disorders, with a unique twist: the network will be community-driven, with researchers working together with persons with lived experience with bleeding disorders, to design and carry out research.



Today, NBDF seeks to build on its proud legacy in an effort to expand and even more impactfully serve the community, fulfill its mission, and achieve sustainability. Strategic directives include 1) Strengthening relationships with chapters, 2) Diversifying funding, 3) Strengthening the capabilities and contributions of staff and board. NBDF plays an important role internationally as well, providing educational resources through its website and its participation on the international council.

NBDF has an annual operating budget of approximately \$20 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 President & CEO, in partnership with the Board of Directors, sets the strategic direction of the organization and directs the senior management team. This person will evaluate strategic long and short-term opportunities, build relationships with chapters, and direct the planning and administration of programs, partnerships, and policy work of the National Bleeding Disorders Foundation. This person will continue NBDF's history of community building, bringing together people and families living with inherited bleeding disorders and learning about their challenges and strengths. As chief spokesperson and fundraiser, the President & 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. A successful President & CEO will continue to have a significant positive impact on the individuals, families and communities living with inherited bleeding disorders, so that they may thrive.

Specific Responsibilities:

1. As President & CEO of NBDF, collaborates with the Board of Directors to shape strategic priorities for the development, implementation, improvement and evaluation of programs, services, and advocacy priorities, as aligned with the core mission;
2. Actively shapes pragmatic, yet aspirational strategy that balances today's challenges with the needs and opportunities in the next 2-3+ years; able to shift strategy based on the needs of the organization and the community it serves;
3. Brings together a diverse set of partners, organizations, individuals focused on or living with inherited bleeding disorders; building community, partnerships to enhance the mission, while keeping persons with inherited bleeding disorders at the center of all decisions;
4. With their staff, establishes and nurtures strong, collaborative relationships with partners (including chapters), based on mutual support, working together to reach shared goals;
5. Recognizes chapters as critical partners for regional efforts and meeting individuals' needs; maintains mutualistic relationship with chapters through regular discussions regarding chapter strengths and needs, effective communication of NBDF strategic objectives, aligning goals and overall direction, support and collaboration;
6. Builds relationships with people and families living with inherited bleeding disorders, community-based leaders and other key stakeholders, looking to learn about needs and the community history;
7. Stewards and builds assets in service to the mission (financial, talent, facilities);
8. Works collaboratively with their team to develop operational plans, assess feasibility and organizational capacity to execute, adapting as needed;
9. Supervises and develops talent and leadership capacity of senior management team, evaluates their individual performance, provides feedback and builds capacity throughout the organization;
10. Shapes a collaborative, inclusive, purpose-driven organizational culture and values, modeling pragmatic, mission-focus, partnership and meaningful community engagement;
11. Promotes strong governance and builds board capacity, assisting the board in recruiting new board directors as necessary;
12. Ensures the financial sustainability of the organization through sound financial management, business planning, and resource development, adapting to the changing financial landscape;



13. Gives overall direction to and supports the fundraising activities of NBDF; works with their team to identify new funding opportunities that align with the organization's mission and strategic priorities;
14. Takes the lead with Board of Directors and Development Committee on major gifts, planned giving, and endowment funding;
15. Works with Board of Directors and President of *Pathway to Cures*, helps raise investment funding;
16. Uses measurements and other methodical approaches to regularly evaluate the work done by the organization, including *Pathway to Cures*, looking at the impact and value, adjusting as needed;
17. Develops and maintains relationships with federal agencies, legislators, relevant government employees, planning and advocacy organizations, payers, various public/private funding bodies and oversees NBDF's lobbying efforts;
18. Represents the organization to its various stakeholders – chapters, funders, partnering agencies, governmental agencies, families, children, and other members of the inherited bleeding disorder community;
19. Builds brand visibility and value; promotes the inherited bleeding disorder communities through direct involvement and through public relations programs; serves as the “public face” of the organization;
20. Participates in national, state, and local organizations that are compatible with the mission, vision, values and direction of NBDF;
21. Launches national research network, bringing together a diverse group of stakeholders for community-driven research.

Key Selection Criteria

The President & CEO, in partnership with the Board of Directors, will have the ability to navigate a large and complex organization with a long and storied history through a period of change. Through its branding, programs, and partnerships, the President & CEO will position NBDF as a source of vital support and pioneering breakthroughs in the field of inheritable blood/bleeding disorders and successfully solicit funds and win major contributions to sustain the organization. An entrepreneurial approach to business management combined with a collaborative spirit are essential, as well as a willingness to learn the community's history, its current strengths and challenges. This person must exhibit the ability to bring together and reach consensus among constituents with sometimes conflicting priorities and ultimately make decisions for the long-term benefit of stakeholders.

Qualified candidates for the President & CEO of the National Hemophilia Foundation will have at least fifteen years' experience combined with a demonstrated track record of increasing responsibility and verified success in managing organizations with multiple stakeholders. The successful candidate must have broad knowledge and competency in bringing together and managing complex groups in a shared endeavor, with particular skills in people leadership, fundraising, political advocacy, finances, and resource management. Demonstrated proficiency in collaboration, strategic planning, and managing a board is required. Experience with groups managing health, wellbeing or inequity challenges is ideal. Candidates may have gained the necessary experience from their work in a range of settings, which may include – but are not limited to – other nonprofit and advocacy organizations; other federated social service or philanthropic organizations that deliver services to the public; agencies or community-based organizations, volunteer organizations, community health centers and more.

A personal connection to inheritable blood/bleeding disorders is not required.

Specifically, the ideal candidate will possess:

- Proven ability and experience to manage a board and senior leadership to collectively achieve mission-related outcomes;
- Proven ability to work collaboratively with existing and potential partners, identifying shared goals;
- Proven ability and desire to engage in fundraising from major donors, foundation, corporations and other sources of contributed income;
- A demonstrated willingness to innovate and the capacity to adapt, pivot as needed;



- 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 nonprofit 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;
- Proven ability to build trust in persons with lived experience with a challenge; able to connect with community members from a range of roles and all walks of life, and learn from them about their history and current experience;
- 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;
- Proficiency working with teams, including teams of experts, and diverse groups – including persons with lived experience; hires based on skill/capability, rather than experience;
- Experienced leading through leveraged impact, working through others to achieve a goal; uses their knowledge of staff to engage, delegate, and lead collaboratively;
- Skilled in facilitating an exchange of ideas and insights, engaging on a peer-to-peer level, collaborating to find solutions, shared goals, agreed upon approaches;
- Proven communicator, able to engage meaningfully with a wide range of audiences;
- Proven ability to nurture an inclusive, purpose-driven culture;
- Demonstrated respect and inclusion of diverse individuals and communities served by, working in partnership with, or employed by NBDF including but not limited to race, gender, ethnicity, social-economic status, and LGBTQ populations.

Personal / Professional Attributes

- Change Management
- Strategic Vision
- Inspiring Leadership
- Excellent Communication
- Internal and External Relationship Builder
- Politically Savvy
- Business/Financial Acumen
- High emotional intelligence (EQ)
- High social intelligence (SQ)
- Learning Orientation
- Growth Mindset;
- Champions Equity
- Impeccable Ethics

NBDF is an equal opportunity employer and does not discriminate on the basis race, color, age, ethnicity, religion, national origin, pregnancy, sexual orientation, gender identity, genetic information, sex, marital status, disability or status as a U.S. veteran. Women and members of historically marginalized groups often do not apply to jobs unless they have 100% of the qualifications. We encourage you to apply if you feel your background and experience gives you what is needed for this role.



Contact Information

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