

# The New England Hemophilia Association's 5-Year Strategic Plan 2021-2026

## Adoption of 2021-2026 Strategic Plan

The NEHA 2021-2026 Strategic Plan was developed during 2020–2021 to cover the operating period of July, 2021 through June, 2026.

The Strategic Plan was approved for adoption by the NEHA's Board of Directors via a vote at the July 13th, 2021 Board of Directors meeting, and recorded in the meeting minutes.

As President of the NEHA Board of Directors, my signature affirms the Board of Directors' approval for adoption of the 2021-2026 Strategic Plan:

Nancy J. Messina

President, NEHA Board of Directors

#### Introduction:

Founded in 1957 around a kitchen table, the New England Hemophilia Association's (NEHA) goal remains the same: to serve the bleeding disorder community in Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, and Vermont. Today we are working to leverage the extraordinary legacy of our past with a renewed passion and capacity to become the NEHA of tomorrow. We have learned a tremendous amount throughout our history and that experience serves to guide us as we set our strategic direction for the next five years.

### **Our Strategic Planning Process:**

This five-year strategic plan was co-created by the Board of Directors and staff through a ten month planning process. Input from our various community constituencies was critical to guide our thinking and direction. The process was informed by results of a SWOT (Strengths, Weaknesses, Opportunities, and Threats) Analysis, as well as input collected from three needs assessment surveys from the greater community, our industry partners, and social workers from treatment centers across New England. In addition to revising NEHA's Mission Statement during this process, we also articulated a vision statement, a set of core values, and a statement on diversity, equity, and inclusion. These values will inform our thinking, guide us in times of uncertainty, and provide fuel for action within our organization. This multi-faceted approach has created a strong framework for NEHA to discern its strategic priorities and goals as it looks ahead to the next five years.

### **NEHA's Mission Statement:**

To create an inclusive community across all six New England states that empowers and enhances the lives of individuals with inherited bleeding disorders and their families through education, support, and advocacy.

#### **NEHA's Vision Statement:**

To improve the quality of life and health outcomes of the New England inherited bleeding disorders community.

#### **NEHA's Core Values:**

NEHA's eight core values drive our priorities, commitments, and organizational decisions. They guide our behaviors, judgments, and how we accomplish our mission.

**Adaptability** - We embrace and recognize change as a path to progress, success, and innovation. We pride ourselves in our nimble ability to adapt in the

face of challenges, while maintaining a constant level of service our community has come to expect.

**Collaboration -** We believe that by working together, we are stronger and can strengthen the fabric of our community. Shared objectives will lead to trust, care, and support.

**Community -** At our core, we believe in serving and fostering an inclusive New England inherited bleeding disorders community. We recognize and celebrate our collective achievements and contributions to embody every sense of this word.

**Compassion -** We cultivate empathy for all people with inherited bleeding disorders and are committed to ensuring everyone has access to support and care.

**Diversity -** We believe that inclusion of ideas, cultures, races, ethnicities, and gender is critical to and essential to the fulfillment of our mission. We are stronger and healthier together.

**Empowerment -** We strive to promote and lift each other up to celebrate our differences, build on our achievements, and use the fuel from our talents, passion, and hard work to do great things to strengthen the programs and services we deliver.

**Excellence -** We believe in driving forward together toward our shared mission to provide the highest standards of programs and support. We plan and execute our mission with utmost pride in our pursuit to serve others.

**Integrity** - We are committed to honesty and transparency in doing what is best for our community. We seek opportunities for collaboration and measure ourselves against the highest standards of fiscal and moral responsibility.

#### **NEHA's Diversity, Equity and Inclusion Statement:**

NEHA stands with the Centers for Disease Control and Prevention in declaring racism as a serious public health threat and denounces all forms of discrimination and intolerance. Recognizing that taking a stand is not enough, we are on a path of exploration and community engagement to ensure that the core

values of diversity, equity, and inclusion are reflected in all NEHA policies, practices, and programs. We believe this is the best way to serve everyone in the inheritable bleeding disorders community, including families and caregivers, throughout New England. We strive to be an organization that seeks equity and works to improve the health outcomes of all people regardless of bleeding disorder diagnosis, health status, disability status, age, race, ethnicity, color, country of origin, immigration status, primary language, religious or spiritual belief, sex, sexual orientation, gender identity or expression, socioeconomic status, veteran status, or place of residence.

#### **Strategic Priorities and Goals:**

## Strategic Priority 1: Enhance Access to NEHA Programs and Services Across the Entire New England Region

## Strategic Goals:

- Meet the needs of all current NEHA members regardless of where they live or receive medical care in New England
- Ensure that the distribution of in-person events across all six New England States meets local community needs
- Provide exclusively virtual events and create virtual options for members who are not able to attend marquee in-person events
- Optimize NEHA's strategic partner relationships with Hemophilia Alliance of Maine (HAM) and Connecticut Hemophilia Society (CHS) to reduce costs and redundancy, respond to community feedback, and better meet the needs of families with inherited bleeding disorders throughout New England
- Create mechanisms for the Board/staff to get better insight into the needs of different NEHA constituencies, with particular attention to the needs of members from rural communities, and help staff prioritize programming

## Strategic Priority 2: Create a More Inclusive and Diverse NEHA Community

#### Strategic Goals:

- Ensure that NEHA Leadership reflects the diversity of the inherited bleeding disorders community in all the New England states
- Identify, engage, and ultimately connect historically underrepresented and underserved individuals with inherited bleeding disorders and those in their networks (such as family members) to NEHA's education, advocacy and support programming across New England

### Strategic Priority 3: Maintain Long-Term Financial Stability for the Organization

## **Strategic Goals:**

- Grow the revenue streams of the organization that are outside of the bleeding disorders community (industry and community members)
- Support the expansion of community-driven fundraising and planned giving
- Continue to expand fundraising opportunities for industry partners

## Strategic Priority 4: Communicate Effectively to Continue Building Trust with the Community and Key Stakeholders

## Strategic Goals:

- Deepen relationships and build trust with our community and other key stakeholders including Hemophilia Treatment Centers, independent hematology practices, industry partners, national bleeding disorders organizations, and other bleeding disorders chapters
- Maintain NEHA's communications strategy that enhances our presence with our constituents, especially with regard to our website, newsletter, and social media

## Strategic Priority 5: Maintain Excellence in NEHA Programming and Continue to be Responsive to Community Needs

#### Strategic Goals:

- Ensure that NEHA only offers programs that are of excellent quality and high value to the community
- Ensure that the event offerings are equitably distributed across and meet the needs of all of the community's constituent groups (families, blood brothers, blood sisterhood, VWD, moms in action, dads in action, teens, new families, seniors, spanish language, race or ethnic-identity-focused, etc.)
- Develop a community-driven events program to empower community members to plan and run small informal events without staff presence
- Understand the mental health needs of our community, work to normalize mental health discussions, and serve the needs of the community based on the recommendations of the NEHA Board's Mental Health Task Force

## Strategic Priority 6: Continue to Enhance the Support Services Available to the Community

#### **Strategic Goals:**

- Continue to expand, define, and determine appropriate staffing for the NEHA Cares initiative (Emergency Assistance, welcome packages for new families, travel scholarships, educational scholarships, medical IDs, other supportive programs)
- Increase outreach and communication to better engage the beneficiaries of the NEHA Cares initiative

### Strategic Priority 7: Continue to Expand and Refine Advocacy Efforts

## **Strategic Goals:**

- Expand, define, and determine appropriate staffing for NEHA's advocacy initiatives
- Deepen relationships with federal, state, and local elected officials
- Work with national organizations and other patient advocacy groups to provide a stronger voice for our NEHA community
- Collaborate with National Hemophilia Foundation, Hemophilia Federation of America, and other organizations to support high-value research efforts and explore other opportunities

### Strategic Priority 8: Grow and Retain NEHA's Exceptional Staff

#### Strategic Goals:

- Ensure NEHA has the staff necessary to deliver on the mission of the organization
- Retain existing staff to the greatest extent possible
- With a focus on long-term sustainability, offer a schedule of events that provides high value and meets the diverse needs of the community, without creating unreasonable expectations for staff
- Engage more volunteers to support staffing of local events and increase feelings of ownership of NEHA throughout the community
- Build a more structured volunteer program that recruits, trains, and retains new volunteers, including teen leaders
- Build upon the committee structure to create more value for the staff (Programming Services Committee, Development Committee, Advocacy Committee/New England Bleeding Disorders Advocacy Coalition (or NEBDAC), NEHA Cares Committee)

#### Implementation:

NEHA will strive to fulfill its mission through the advancement of these strategic priorities and goals over the next five years. To achieve this, we will develop an annual Action Plan with targeted objectives that measurably and meaningfully move the priorities and goals forward. We have already taken steps to address some of the more urgent priorities, including starting a *Mental Health Task Force* and a *Diversity, Equity and Inclusion Task Force*. The Board of Directors and staff will assess our progress at regular intervals, and we will report our progress to the community annually.

#### **Conclusion:**

This is an historic moment for NEHA. The needs of our community are shifting as the treatment of bleeding disorders and the current health care landscape continues to dramatically change. In addition, the COVID-19 pandemic has posed unprecedented challenges to us all. NEHA is rising to the occasion, embracing this extraordinary opportunity to evolve and deliver on the full promise of our mission now, and tomorrow.

The next five years will be an exciting time that will shape the future of our organization. We believe this strategic plan will provide the direction and inspiration to guide us to a brighter, healthier, and more equitable future.