

September 24, 2019

Rich Pezzillo, CSO Chair
Charlene Cowell, CSO Vice Chair
Debbi Adamkin, CSO Secretary
Fran Haynes, CSO Treasurer
Sue Martin, CSO Advisor

Dear CSO leadership,

Thank you for the time and effort put into the comment letter sent to our organization and NHF. We understand that your time as executive directors is precious, and every moment spent on the CSO letter is time away from your local administrative and fundraising duties. Therefore, we take your comments very seriously and agree that all nonprofits in this space should work together to achieve the common goal of a stronger bleeding disorders community.

We value and encourage honest feedback about the performance of our organization, programs and services. Our mission of assisting, educating and advocating for the community is truly the compass that guides our daily actions. As such, serving the needs of our Member Organizations is a pillar of how we achieve that mission. Not a day goes by without staff members engaging directly with our 50 Member Organizations. Therefore, we view your comment letter as another opportunity to achieve an open dialogue with our partners in the community. For that, we thank you.

By taking your concerns and suggestions into consideration, we have identified areas in which we can improve organizationally. To that end, where we are able, we identified how we will address those gaps in the coming year. In areas involving our organization and NHF, where it makes fiscal and logistical sense, we are committed to working collaboratively to strengthen the community. This reply is structured in the same format as your letter to easily correlate our responses to your respective comments.

Trust

We are deeply saddened that our Member Organizations have not felt heard. Not only do we hear the voices of the local organizations within our day-to-day work, but we offer a seat to each Member Organization on our Board of Directors, the governing body that sets the mission and direction of HFA and the most prominent platform within the organization. We find this peer-to-peer learning and interaction an effective means of knowledge transfer that fully supports the community. Moreover, we recognize that a single nonprofit is not the keeper of all knowledge, and we evolve and grow as a community by listening to the voices of others. Our voices and stories make us who we are, and we truly value that dynamic.

In the same section, you mentioned difficulty in accessing our financial information. We encourage you to use the current systems in place to access the information or simply ask if further clarification is needed. Transparency is very important to us. Our commitment to transparency, accountability and the financial health of the organization was recognized by Charity Navigator when we were awarded the Four-Star Charity designation, in which less than 1% of organizations evaluated receive a perfect score, and when we received the Platinum-Level Seal of Approval by Guidestar. Also, as a nonprofit organization, we are obligated to file a form 990 annually with the IRS. These completed forms are made publicly available through the IRS, but in an effort of seeking additional transparency, we go further by publishing them on our website alongside independent financial audits and annual reports. Furthermore, our open-format board of director meetings provide a financial overview of the organization, making our cash flow, balance sheet, and additional financial information readily available to the community.

Local Chapters' Oversight Responsibilities for the National Organizations Advocacy

We, too, believe that a strong national patient-centered voice is critical to moving the community forward. A seat on the board gives Member Organizations operational oversight and inherently accomplishes the five areas of oversight listed. Additionally, an extra seat for the CSO is redundant and not warranted simply because the CSO is represented by each Member Organization currently filling a Board seat. Moreover, an extra seat for the CSO does not fit into our federated model with each Member Organization filling a single seat.

Governance of National Organizations

We agree that the needs of the community due to emerging therapies will inevitably change the landscape. All organizations, nonprofit and for-profit alike, within the community must change to meet our new normal. The suggestion of a merger between the two national organizations is a topic which has piqued the interest of some and caused considerable concern among community members. We believe there is a middle ground where our organization and NHF can coexist as two independent organizations, leveraging the strengths of each to better serve the community. We see immense value in our existence as an independent national nonprofit organization and our unique patient-focused position in the community. We also value our rich history and partnership with NHF. As the landscape changes, we look forward to serving the community in new and dynamic ways and will continue to forge a closer relationship with NHF. A closer relationship among the national organizations is deeply beneficial especially when it keeps the best interest of community members in mind.

Additionally, we are moving forward with a search firm to hire a new full-time President & CEO to fill the vacancy at HFA. We are eager to extend an offer to a dynamic leader with an innovative vision for our organization's future.

Advocacy

We believe that the voice of the community is only amplified by the presence of multiple national and regional organizations. Our organization and NHF currently collaborate on many levels on policy and advocacy matters, and in such, have a unified voice. The recent Bayer recall is an example of such collaboration. We have jointly worked together to communicate with key audiences such as Bayer and Member Organization executive directors and will work jointly with the FDA (meetings are being scheduled). As such, both organizations agree on the messaging and approach.

The confusion experienced by legislators you mentioned is not an accurate representation of our community's presence in Washington. We have a robust collaboration with NHF in policy and advocacy efforts and work with a unified voice. Our policy and advocacy teams work together to ensure we are providing assistance at the state and local level by not duplicating efforts, and therefore, acting as good stewards of our funds (e.g., dividing attendance at state legislative days; we do typically both attend planning summits which again, helps ensure unified voice). Both organizations participate in a number of key coalitions and have signed on to joint comment letters to both federal and state governments. We work cooperatively on blood safety matters as leading members of the APLUS coalition as well as working together on policy issues concerning the advent of novel therapies, often providing joint comments (e.g.) to FDA and ICER. Both organizations, as a united voice, have commented on many federal proposed rules. Some examples include our comments on NBPP, our comments on Medicaid managed care rule, and our comments on Medicare Part B and Part C rule.

We have suggested and are more than willing to have a joint planning session with NHF to continue to explore potential opportunities. During such a meeting, we can map our campaign, communication, and policy activity strategies and develop a calendar for attendance and coverage of federal and state advocacy efforts. NHF is amenable to the idea as well.

NEXT STEPS

We will contact NHF leadership to schedule a planning session to explore opportunities for collaboration and partnership within our advocacy efforts. During this meeting we will discuss and outline our campaign, communication and policy activity strategy and develop a calendar of attendance and coverage of federal and state efforts.

Regarding the comment on funding local chapter advocacy, we do not provide grants for Member Organization's advocacy efforts. Our support is our experience, education presentations, toolkit, etc.

We know that some allied patient groups that participate in our coalition partners (SAIM, Burritos) have state level government affairs professionals that cover a certain region, for example one person may cover 6-8 states in the Midwest. The state affiliates of these allied

patient groups, however, tend to be chapters of the national organization rather than independent affiliates, as is the case of our Member Organizations. As such, their policy goals are set by the national organization rather than at the state level. While it is possible based upon strict rules governing 501(c)(3) lobbying activity, a thorough analysis would be necessary before moving forward with such a recommendation. According to the IRS, “In general, no organization may qualify for section 501(c)(3) status if a substantial part of its activities is attempting to influence legislation (commonly known as lobbying). A 501(c)(3) organization may engage in some lobbying, but too much lobbying activity risks loss of tax-exempt status.” The IRS considers a number of factors including time spent on lobbying, by both employees and volunteers, and expenditures to influence legislation such as travel costs, printing costs and other costs incurred to influence legislation. The IRS can determine if the lobbying activity is substantial and the organization could lose its 501(c)(3) status or pay taxes on the expenditures used for lobbying.

The current practice of state-level Member Organizations and coalitions hiring legislative counsel is working. Our organization, as well as NHF, provides support at the state level so the Member Organization executive directors, staff, and volunteers have the resources they need to do the work with their respective state legislatures. Additionally, we established the Advocacy Leadership Council to build grassroots support for the Member Organizations in their legislative advocacy efforts.

NEXT STEPS

We will contact NHF to discuss hosting a workshop to teach legislative tracking and how to address legislative flashpoints with Member Organizations and Chapters. Additionally, our team will add a policy pre-conference training at Symposium to our agenda which is currently being developed. Finally, regarding a joint Washington Days, our staff is open to being part of the planning and presenting should NHF deem necessary. A discussion on this could also take place during the planning session recommended earlier.

Chapter Support

We will continue to communicate with executive directors and community members to identify gaps in service and use the feedback to guide our plans for future programs to meet their needs. We are proud to offer blended learning opportunities through face-to-face and digital modalities utilizing Learning Central and other online resources to provide targeted training modules for Member Organization staff and alternative ways of learning for community members. We invite executive directors to share ideas for programs which they find to be timely, relevant and valuable and collaborate with us to develop them. We have always encouraged and welcomed this type of dialogue with our Member Organizations.

NEXT STEPS

We will conduct a survey amongst our Member Organizations inviting them to share ideas for programs which they find to be timely, relevant, and valuable.

Along with the help of thought leaders from Member Organizations, we have taken steps toward pooling resources to support their staff. The creation of a Google Drive has made it possible for them to share resources amongst one another, avoiding the need for an individual to recreate a resource or document that covers topics such as event ideas, policies and procedures, job descriptions, etc.

Our Member Portal and Learning Central are valuable resources for staff of Member Organizations and board members, containing information about accessing our programs, documents for board meetings, and other valuable resources. We strongly encourage the use of these tools and the sharing of feedback on how we can improve them.

NEXT STEPS

We will continue to make improvements upgrading the Member Portal and include leadership development modules in Learning Central.

We acknowledge the frustration that Member Organizations have with the many liaisons for the various teams within our organization. Given the scope of our work and various departments that house multiple programs and initiatives, we are a growing team. Despite our growth, our team is close-knit and connected. Anyone on staff could immediately connect you to the appropriate contact, should they be asked. We have created a staff page on our website which helps to quickly locate the respective staff member by role and responsibility.

NEXT STEPS

To address the need for clarity around direct contacts for Member Organizations, we will add an updated organizational chart and publish a list of liaisons and their contact information to the staff page within the Member Portal.

Fundraising

We, too, see immense fundraising opportunities in the coming years. However, our approach to fundraising has been aggressive. We hired additional staff, professionalized the department, provide quality continuing education and adhere to industry-wide best practices. In future, we will continue to professionalize fundraising as a worthy endeavor needed for the financial health of the organization.

We agree that nonprofits should diversify their funding streams to ensure fiscal stability. That said, it is not uncommon for nonprofits to be largely funded by one source. Universities are often largely funded by alumni while hospitals are largely funded by corporate donations or private and government grants. Corporate donations and private/government grants largely

fund nonprofits in the bleeding disorders community. This is a normal funding model within healthcare fundraising and should not be automatically considered a weakness or threat.

Corporate donors make up our largest revenue stream, though our pool of donors is diverse, and their funding interests and commitments are varied. Over the years, we have made many efforts to build new relationships with donors and diversify our funding streams while still forging strong partnerships with our corporate funders. Efforts include a greater focus applying for private and government grants, launching a peer-to-peer fundraising platform, increasing solicitations to individual donors and building partnerships with corporations outside of the healthcare industry such as our recent partnership with runDisney. We believe that setting arbitrary percentage goals such as you suggested is an ineffective strategy to building a strong funding model. Our goal is to increase funding across all revenue streams to be able to better serve our mission and the community.

NEXT STEPS

We will continue to work to diversify and increase our funding streams to ensure optimal fiscal health of the organization. However, we understand that sowing seeds today may not reap rewards tomorrow. Diversifying organizational funding requires immense strategic planning and takes time. These realities are not new to our team and we have been working hard, and will continue to do so, to strengthen the fiscal health of the organization.

The CSO is correct in saying “our community’s history is rich, complicated, tragic, and hopeful.” We believe no one person or organization can define our community’s story. Our community’s history is the sum of all parts, not one period or event. Pre-factor immobility and death for patients, the HIV crisis, improved treatment through prophylaxis, innovation and optimism in an era of gene therapy...this *is* our story. In our fundraising efforts, we use the layers of complexity in our story to appeal to respective audiences. Some donors gravitate to heartfelt stories while others gravitate to logic or hope. The Smithsonian, for example, was drawn to our History Archive Project due to the depth of our community’s rich history. We truly understand our “why” and work each day to connect donors with the organization in meaningful ways that impact our fundraising goals. Our work to share the community’s story has proven successful time and time again and has provided our organization with the resources to serve our mission.

NEXT STEPS

We will begin to plan a workshop for Member Organization staff focused on storytelling and how to use multiple stories to appeal to different donors.

We work day in and day out to increase our funding revenue to support the community. A unified national bleeding disorders organization does not guarantee a greater share of charitable healthcare support. However, the most effective method to increase revenue streams from charitable healthcare sources is through innovative and patient-focused projects. We are actively pursuing these endeavors.

Programming

Our programs team has reviewed the list of programs that NHF published on their website. While many topics or themes could be perceived as duplicative, our delivery and reimbursements differ. We often hear from our Member Organizations that our system is easy to navigate, and our staff is very accommodating. We would be happy to engage in ongoing conversations with NHF's educational team to determine areas of opportunity for collaboration as well as outline their programmatic request and reimbursement process.

NEXT STEPS

We will contact NHF's leadership team to set up a time for our educational/programs teams to meet to determine areas of collaborate and how we can align the programs being offered. During this time, we will also discuss the reimbursement process currently being used and areas for improvement.

While there are a variety of industry programs available to Member Organizations, many of them are branded. We provide unbranded programs with speakers and content which can be adapted to the needs of the local audience. We receive funding based on our proposed program cost and predicted number of program sessions to be provided to local Member Organizations. We then use those funds to provide reimbursements to Member Organizations for sessions conducted in their local area. We recognize the need to provide an increase in educational programming to our Member Organizations and are working to increase the number of available programs. Our national educational programs, which are funded individually, only take place when full funding is in place.

Additionally, we use a variety of speakers to deliver our vast array of educational sessions including our staff and local subject matter experts who may need to travel to present. Our program liaisons work with the Member Organization staff to customize the presentations/speakers to meet the needs of their local community.

NEXT STEPS

Our plans for 2020 include using some of our current coalition relationships with other non-profit organizations to leverage our collective wisdom and provide new, innovative programs, and avail ourselves of new subject matter experts to use as speakers.

We currently invite Member Organizations to provide us with dates for large meetings and events to be added to our Google calendar which allows us to take local event schedules in to account when planning national events. We will work to provide Member Organizations with advance notice of national programs and collaborate with them to recruit participants who will most benefit from participation as well as those who will bring their experience back to their Member Organizations to help grow their local programs. Finally, in the past, we reached out to NHF, the Coalition for Hemophilia B, and Member Organizations when planning events such as

Symposium or our Patient Fly-in to ensure our dates do not conflict with their events. We will continue to do this.

Research

Research for a cure for bleeding disorders is priority for many institutions, but it is not, and should not be, the only focus for our community. We are not conducting or developing research projects that are directed toward the sole purpose of finding cure: our projects are focused on and conducted with the purpose of improving the quality of life for people living with a bleeding disorder. Our research program is patient-driven, and our projects are patient-centered. As an advocate and steward of the community's voice, we are uniquely positioned to lead research efforts that champion patient-centered outcomes that go beyond the scope of a traditional clinical trial. We want to be sure that our efforts are complementary and continue to focus on the needs of our community.

Collaboration is a cornerstone of our research program and our team has always pursued partnerships with other research entities. In April, we convened representation from ATHN, the CDC, PCORI, and NHF, and invited the NHLBI, to provide an overview of what is being done in research within the community and how we can collaborate.

NEXT STEPS

In 2020, we will expand upon this by hosting a workshop for these groups and others, to discuss collaboration efforts further with the goal of presenting our findings at our annual Symposium. We plan to continue to collaborate to take a more comprehensive look at the research landscape to identify opportunities to invest in innovation and to explore options such as creating a pipeline for patient-centered research. Additionally, we have had a partnership with ATHN to use data from our Sisterhood mobile app for use in their research projects.

Sharing research findings in clear and understandable language has been a top priority of ours and is vital to our community. We believe providing education opportunities to better understand the language and jargon of scientific research is an important step towards an empowered community. To these ends, we hosted a research poster session during our annual Symposium to provide community with the opportunity to meet the researchers who could translate their efforts in person in a relatable and engaging format. We have invested significant resources into the development of courses within the HFA Institute that take a deep dive into patient-centered outcomes-based research, comparative effectiveness research, how to learn about research in the community, how to identify helpful resources and how to gain a foundation in emerging therapies. We continue to revise and update this information collaborating with key stakeholders throughout our community.

Our organization is aptly positioned to take on a mixed method approach to research, both qualitative and quantitative. By using qualitative approaches such as focus groups, within a

behavior theory construct, we can capture an individual's voice and better inform our choices supporting education, advocacy and even how to facilitate patient engagement in research. The expertise and approach of ours is unique and complementary to the other researcher organizations within our community and we are aptly positioned to drive patient centered research initiatives and facilitate patient engagement in these efforts.

NEXT STEPS

We will continue to find unique ways to communicate research findings back to our community and present at scientific and community-focused conferences.

Finally, we believe that suspending participation in research efforts is not a constructive way to address your concerns. Please remember, it is our duty to ask questions or help find answers to the most pressing problems facing our community.

Our Final Thoughts

In closing, we thank you for the opportunity to provide answers to your comments. We, too, are optimistic about the future of our community. As such, we encourage more collaboration between the national organizations and Member Organizations. We strongly believe in partnerships as evoked by our federated model, not competition.

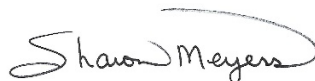
Additionally, we are receptive to feedback about our services and performance and want to hear from our Member Organizations when they see areas of opportunity. Moving forward, we will keep healthy and strong lines of communication open because we know it is a valuable tool for growth.

In the end, we have a shared purpose to improve the lives of people living with a bleeding disorder. We will continue to focus on our mission to assist, educate and advocate for the bleeding disorders community. Together, we are strong. **Together, we are family.**

Warm regards,



Josh Hemann
Board Chair



Sharon Meyers, M.S., CFRE
Interim President & CEO