



## **NATIONAL HEMOPHILIA FOUNDATION**

*for all bleeding disorders*

### **Update on the NHF Transition Process**

This report is intended to bring the full NHF Board, chapter leaders and other members of the community up to date on the recent activities and progress of the transition team, including the meeting with chapters and other community representatives that was held in Tampa. It is organized according to the four subject areas addressed by the respective working groups. However, greatest attention has been given to the “organization” area, since this is the area that was emphasized in the Tampa discussions. Within each area, we’ve reported on the key recommendations of the working group going into the Tampa meeting based on prior discussions. You may have seen some of these recommendations before, and they were reported on as well at the Tampa meeting. Also included where applicable for each respective category is a general description of the discussion in Tampa, the results of the discussion, the response of the transition team and follow-up. Again, based on the agenda in Tampa, the latter items apply primarily to the organization area.

#### **I Constituency Working Group** Chair - Shirley Wilson-Oslund

##### **Key Initial Recommendations to the Transition Team**

The overall consensus of the group was to be responsive to the community’s call for broader access and input with regard to important NHF decisions and processes. Based on that consensus, the following were recommended:

- Distribute a survey soliciting input from constituents, including consumers, chapters and associations leaders, MCHB regional coordinators and HTC professionals regarding the process by which the NHF Board of Directors will be reconstituted. (This was completed, and submitted by some, but the survey can still be completed and submitted online.)
- Convene a caucus during the On the Road weekend (April 30) in Tampa, Florida. The goal of the caucus will be to work toward building consensus among stakeholders in the bleeding disorders community with regard to the aforementioned board reconstitution. (This was completed.)
- Convey to the Organizational Working Group, whose tasks include framing the Board reconstitution process, the group’s strong sense that NHF members have a strong desire to have significant input in that process. (Also completed.)

## II **Communications Working Group**

Chair – Debby O'Connor

### **Key Initial Recommendations to the Transition Team**

- Communication should utilize messages that are positive, forward-thinking, consistent and meaningful. Communication with constituent groups should be regular enough so that they feel included in the happenings of NHF, yet not so often that they become mundane and are ignored.
- An update letter from Dr. Metz should be distributed, making reference to the support of the MASAC members and others for the changes in progress and other actions of the transition team. (This was completed.)
- MASAC members should be asked to participate with the team in drafting and distributing a letter to the community that would clearly indicate their support for the efforts of the transition team and their confidence in the process going forward. (This was completed.)
- NHF Board meeting minutes, minus any information considered to be of an executive nature, should be accessible to the community. This could be accomplished by the posting of this information in select places, including the chapter-to-chapter extranet system that will be launched soon, as well as via eNotes. They should be distributed in a format that will allow chapters to reprint them, all or part, in chapter newsletters.
- The Board should be open to suggestions from the community on topics to be discussed at Board meetings.
- The Board should continue regular communications with key industry contacts, keeping them apprised of transition team activities and other developments.
- All important communication should be made available to consumers, chapters, industry, including factor companies and home care, and donors in formats that are accessible to particular groups, including but not limited to posting to the NHF Web site.
- The transition team should create an open forum for discussion of the current status of NHF at either/both Tampa and Seattle meetings (completed). The announcement and meeting itself should set a positive tone and the focus should be on the steps taken to avoid conflict in the future (completed).
- The transition team should encourage an ongoing, open exchange of information between member chapters and NHF. The survey conducted by Rita Gonzales is one example of the kinds of processes that should be encouraged and continued. One

suggestion was that we begin requesting certain basic information annually at the time of membership renewal.

### **III CEO Search Working Group**

Chair – Stephen Bender (Presented in Tampa by Rita Gonzales)

#### **Key Initial Recommendations to the Transition Team**

- Empower the five NHF department directors to convene as a “Staff Council,” in lieu of another interim CEO. The council would meet as often as necessary to address all operational concerns and day to day issues, with Steve Humes, director of research, serving as chair.
- Identify and engage an appropriate search firm by April 23.
- Identify two or three viable candidates for the position by August 27.

### **IV Organization Working Group**

Chair – Paul Haas

#### **A Key Initial Recommendations to the Transition Team**

- The size of the NHF Board of Directors should be set at 15, with staggered terms of service for each of three groups of five. One-third (five) will receive a one-year term, one-third (five) will receive a two-year term and one-third (five) will receive three-year term.
- The Board should include members of the bleeding disorders community, as well as individuals from outside the community. All Board members should possess the skills, talents and other qualifications that will be predetermined as necessary for an effective board.
- The nominating committee should consist of five Board members. The nominating committee will be guided by a Board policy, which will spell out the goals of the Board, the commitment of the Board to its constituencies, the channels of communication between the Board and the constituencies and the process by which nominations will be sought.
- The Board should be a governance board and not an operational board.
- The new Board will have as one of its mandates the establishment of a clear description of the nature of the relationship between NHF and its Board and each of its chapters. This description should include an enumeration of the rights and responsibilities of both parties. The Tampa caucus will be a first opportunity to solicit input for the process of establishing this description.

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- The new Board should include some of the current Board members to maintain a sense of history and continuity.
- There should be an audit committee that will serve as a committee of the Board and will work closely with the auditors and report directly to the Board.
- Per an earlier discussion at an NHF Board retreat, a new conflict of interest policy should be implemented.
- NHF's mission includes the promotion of scientifically-proven research and policies with regard to the treatment of hemophilia and other bleeding disorders. Activities that would put NHF in the position of appearing to make decisions on these matters using any criteria other than science will be deemed a conflict of interest. Similarly, activities by Board members or staff will be considered conflicts if, in the name of the organization, they promote or advocate a specific therapy for reasons other than good science or medicine, or contribute to private inurement.
- Individuals whose conflicts would be ongoing, (ie, of a nature that would compromise their ability to serve on a continuous basis), shall not be permitted to serve. Individuals whose conflict pertains to a specific issue will recuse themselves from discussion and voting on matters relevant to those issues
- The current Board should adopt bylaw amendments to reinstate the chapter organizations as voting members to allow the organization to come into compliance with New York state laws. Thereafter, the members will be asked to approve an amended and restated Certificate of Incorporation. The new Board will have as one of its mandates the drafting and approval of a new set of bylaws that should incorporate the work of the transition team and reflect as well the concerns and advice of legal counsel.

### **B Group Discussions in Tampa on the Organization Working Group's Recommendations**

As previously stated, the caucus attendees in Tampa were presented with the recommendations of all of the working groups, but only the Organization Working Group's recommendations were identified as a major area for discussion and input at that session. The rationale for this decision was the need to prioritize tasks, with the Organization Group's issues having been identified prior to the meeting as the first and most urgent priority. The understanding is that there will be additional opportunities for input on the other issues at a later time.

The discussion process included allowing the participants to divide into groups around ten tables, and then dividing the recommendations into three broad categories. Each table group was asked to discuss and provide detailed reactions to the recommendations in one of the three categories and was encouraged to offer alternatives to any or all of the recommendations. The structure ensured that each

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group of recommendations would be analyzed by more than one table group, and participants were allowed to choose their tables based on a particular interest in the issues being discussed. Following the individual table discussions, the groups came together to report on and share the highlights of their discussions.

The goal was not to achieve broad consensus around all of the recommendations; to do so within the time allotted would have been impossible. General agreement did emerge around of the recommendations. On the issues related to Board size and composition, many agreed that the size should be set at 15, or thereabouts, with staggered terms for each of three groups of five. There was general agreement that the board should include members from within and outside of the bleeding disorders community, and that all board members should possess a set of prerequisite skills, to be enumerated later. There was also broad agreement that the Board should be a governance board and not an operational board. Participants seemed mostly comfortable with the recommendations on giving the new Board the mandate of working with chapters to clearly define the Board-chapter relationship, including the immediate legal need to reestablish the status of chapters as “members.”

The area around which the most “contention” arose was the subject of the nomination and election process, and specifically the role of the chapters in that process. Participants were divided as to whether the process should be partly chapter-driven and partly board-driven, or if it should primarily be determined by the chapters. Polling was conducted, and by gradually eliminating the choices that received the least support, the majority view that ultimately emerged supported giving chapters a major role in the process. In addition, there was strong feeling that the nominating committee should include both NHF Board members and non-members, applicable laws permitting.

### **C Response of NHF Board Members**

The six members of the current NHF Board that were in attendance, all of whom also serve on the transition team, met following the group discussions on the Organization Team recommendations and developed a response, which was presented by NHF President Richard Metz, MD, during the dinner session. The response included the following points:

- We agree that if governing law permits, the nominating committee should include some non-board members, and that if need be, the bylaws should be changed to allow for that. If the law does not permit this, a nominations advisory committee should be formed that will include chapter representation. The advisory committee will work very closely with the nominating committee of the Board.

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- As discussed, Chapters should be formally identified as voting members of the foundation for the purpose of electing the new Board.
- A significant number of current Board members that are serving on the transition team should be identified in the nomination process for continued service on the new Board.
- At least one-third of the new Board should be new members.
- The Board size should be 15, with emphasis on ensuring diversity.
- There should be more candidates nominated than there are available slots to ensure a meaningful election process with genuine options.
- Board policies must be established to hold Board members accountable for their actions.
- The Board should make a strong commitment to improving all communication.

### **D Schedule for Follow-up on Key Organization Team Recommendations**

- The transition team will immediately begin considering caucus results.
- Transition team will discuss bylaw changes during a May 19 conference call. The changes to be considered include:
  - identification of chapters as voting members;
  - change in the notification requirement for general membership meeting from 60 to 20 days;
  - permission of non-board members to serve on the nominating committee if permitted by law, or form advisory committee if not.
- Nominating committee will be formed at June Leadership Weekend and Board meeting.
- Board will vote on proposed new Board selection process and bylaw changes at that meeting.
- Following expected approval, a call for nominations will be issued.
- By Sept 30, “Chapter Members” will vote for new Board, which will be installed shortly thereafter and begin working immediately to implement new mandates and develop policies based on those mandates.
- New CEO to be selected by August.