



# Strategic Plan

2011-2013

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## Purpose of the Plan

In January 2011, the Hemophilia Society of Colorado hired Emily Davis, MNM, to serve as its executive director. Following three years of being solely volunteer-led the organization and functioning without a current strategic plan (previous plan covered 2005-2007), the board of directors and executive director determined that a 2011 priority was to conduct an in-depth strategic planning process.

Several big questions are facing HSC in 2011 related to: merging with the National Hemophilia Foundation (NHF); transitioning programs from the Hemophilia Treatment Center; fully supporting its membership through programs; expanding staffing; building an effective volunteer engagement program; establishing internal systems and structures to support the organization and; financing ongoing operations with a sustainable and diverse approach.

The board and staff wanted to ensure that member and community voices related to these issues were included in the future vision goals and objectives and wanted to encourage full participation from HSC's leadership in the process. To support both of these goals, HSC hired interSector Partners, L3C to conduct a stakeholder input process and provide consultation/facilitation of a planning retreat.

The HSC strategic plan, the result of a multi-month process outlined in detail on the following page, will support HSC's advancement from what is essentially a place of nonprofit start-up/growth stage into a growth/maturity stage over the next three years. The plan includes a three-year vision for HSC and the supporting goals, objectives and action plans to guide the HSC leadership team in achieving this vision.

## The Planning Process

The strategic planning process included a number of key steps designed to engage stakeholders, examine internal capacities and understand perceptions of HSC in the community. Highlights of the process include:

**March 2011**

- interSector Partners, L3C selected by the Hemophilia Society of Colorado to serve as its strategic planning consultants and facilitators
- Document and information review conducted
- Key stakeholder interview protocol developed
- Key stakeholder telephone interviews conducted
- Member survey drafted

**April 2011**

- Key stakeholder telephone interviews conducted (continued), report developed
- Member survey administered, report developed
- Member telephone interviews conducted, report developed
- Strategic planning pre-retreat packet submitted to board and executive director
- Strategic planning retreat held on April 23, 2011

**May 2011**

- Draft strategic plan submitted to HSC leadership by iSP
- Executive director reviews and submits feedback / revisions to iSP
- iSP revises strategic plan and submits "final" document for board review

**June 2011**

- HSC board of directors conducts final review and adopts the strategic plan

## HSC Overview

### HSC's History

HSC is a local chapter of the National Hemophilia Foundation that has worked to improve and enrich the lives of people living with hemophilia and other bleeding disorders for over 30 years. The HSC works closely with the Hemophilia and Thrombosis Center (HTC) and together the two provide a variety of educational, supportive, and interactive programs for the bleeding disorder community. Programs, services and events include:

- Academic scholarship program
- Advocacy programs
- Educational programs
- Mile High Summer Camp (primarily led by HTC)
- Colorado Walk for Hemophilia
- Financial Assistance Program
- Hispanic & Latino Programming
- Women's Programming
- Black and Blue Event

HSC is led by a board of directors and an executive director, and over many years has been a primarily volunteer-run organization. HSC with support from NHF has been able to hire an executive director and has created committees as part of an overall infrastructure improvement. Committees include:

- Advocacy Committee
- Board Development Committee
- Fund Raising Committee
- Industry Advisory Committee
- Program Services Committee

At this time, with support from NHF and industry funders, HSC is financially stable but needs to diversify its funding sources for long-term sustainability. The board and staff are committing to diversifying their funding sources by crafting and implementing a fundraising plan and seeking support from experts in the field.

### HSC's Mission

The Hemophilia Society of Colorado is dedicated to enhancing the quality of life in the Rocky Mountain bleeding disorder community through advocacy, education, and emotional and financial support. This includes creating public awareness, promoting excellence in medical care, and providing a support network for individuals and families.

## S.W.O.T. and Current Reality

### S.W.O.T.

The board of directors and staff of HSC conducted a S.W.O.T. analysis based on the feedback and input it received from key stakeholders and HSC members. The S.W.O.T. is an in-depth exploration of the organization's strengths, weaknesses, opportunities and threats / challenges typically examines internal strengths and weaknesses, as well as external opportunities and threats. The HSC board and staff included internal ideas and concerns within their listing of *threats* which are termed as *challenges* below.

The following S.W.O.T. includes highlights from the stakeholder input reports available in Attachment A.

Strengths	Weaknesses (Areas to Improve)
<ul style="list-style-type: none"> <li>• Education / information</li> <li>• Social interaction</li> <li>• Financial support</li> <li>• Programs (<i>camp, events</i>)</li> <li>• Executive Director</li> </ul>	<ul style="list-style-type: none"> <li>• Programs (<i>HTC, access needs and prioritize</i>)</li> <li>• Funding (<i>amount and diversity</i>)</li> <li>• Communications (<i>internal and external</i>)</li> <li>• Volunteer engagement</li> <li>• Board development (<i>people from outside the community involved</i>)</li> <li>• Organization</li> <li>• Using HTC as a crutch</li> <li>• Knowing our members (<i>who, interests, etc.</i>)</li> </ul>
Opportunities	Threats & Challenges
<ul style="list-style-type: none"> <li>• Advocacy (Washington Days, Colorado Legislative Day, Advocacy Committee, ED relationships with legislators (<i>mobilize our community to advocate</i>))</li> <li>• Expanded programming (<i>more, new audiences</i>)</li> <li>• Industry relations</li> <li>• Member communications</li> <li>• Align with healthcare rather than only bleeding disorders</li> <li>• Volunteer development</li> <li>• Pipeline to board service</li> <li>• Define HTC – HSC partnership generally</li> <li>• Expand geographic reach</li> <li>• Diversified funding</li> <li>• National Hemophilia Foundation</li> </ul>	<p><b>Threats (<i>external</i>)</b></p> <ul style="list-style-type: none"> <li>• Merging with NHF (<i>loss of autonomy, tie to NHF struggles</i>)</li> <li>• Visibility re: bleeding disorders (<i>changing nature of disorders</i>)</li> <li>• Funding cuts</li> <li>• Rapidly changing industry</li> </ul> <p><b>Challenges (<i>internal</i>)</b></p> <ul style="list-style-type: none"> <li>• Entitlement, self-interest</li> <li>• Diversity of members</li> <li>• Burnout</li> <li>• Focus</li> </ul>

The stakeholder input process conducted as part of HSC's strategic planning explored a number of additional stakeholder perceptions and opinions related to HSC, its mission, programming and community engagement. Reports outlining the stakeholder interviews, member survey and member telephone interviews are attached to this document.

## Three-Year Hemophilia Society of Colorado Vision

HSC carefully considered its current functions, stakeholder and consultant input, and board/staff knowledge of HSC operations. The board and executive director created a vision for what the organization will look like by December 31, 2013. The vision is a three-year step on the path to HSC's path toward fully realizing its mission, vision and values and better serving members of the local bleeding disorder community.

By the end of 2012, the Hemophilia Society of Colorado has set goals to:

- Engage more individuals from the bleeding disorder community.
- Expand funding sources to be stable, reliable, and diverse.
- Maintain funding for one full-time executive director and raise funds for one additional FTE and Western Slope staff member.
- Serve as a model chapter as part of NHF.
- Establish reliable programs with opportunities for growth.
- Transition Summer Camp from HTC to the Hemophilia Society of Colorado.
- Execute strong and mobilized advocacy efforts on a national and state level
- Offer all programs in both English and Spanish.
- Develop a clear and vibrant volunteer program with outlined roles and responsibilities.
- Increase board participation by at least 10 and up to 15 board members.
- Develop the existing committees and meet on a consistent basis.
- Create comprehensive policies and procedures.

## Guiding Values

At its April 23, 2011 retreat, the board of directors and executive director outlined several guiding values for the planning process. Guiding values are those ideals that the board and staff agree to uphold in all activities, actions and interactions over the next three years. The guiding values will be revisited during the strategic plan update in December 2012 and again upon completion of the three-year strategic plan.

These values will be shared with the HSC membership and were taken into consideration during the development of the three-year goals and objectives (see next page).

HSC's Strategic Plan Guiding Values are:

- Ask questions
- Set boundaries
- Be transparent
- Maintain high standards
- Demonstrate accountability
- Look at other models
- Be flexible
- Share resources

## 20-Month Goals and Objectives (May 2011—December 31, 2012)

The following goals, objectives and associated action plans (see Appendix D) represent the board and staff's exploration of the question "What will it take to achieve the vision?" Taking into account HSC's current reality, S.W.O.T. analysis and stakeholder input the board and staff developed the following goals and objectives to link today's activities and organizational life stage with its three-year vision.

The strategies and objectives outlined are intended to be accomplished in 20 months, or by the end of December 2012. At that time, HSC will revisit the goals outlined for achieving the three-year vision. The board and staff may, at that time, revise goals and objectives to reflect their existing circumstances and will create a new action plan for the last 12-months of the three-year strategic plan (January—December 2013).

**Please note:** Each strategy is important individually and in conjunction with all other strategies and goals. They are not organized in order of importance. The numbers represent a tracking mechanism for translating strategies and objectives into the [action plan](#) and organizational work plans, not a priority ordering.

### Goal 1: Prioritize board development

**Objective 1.1:** Create a pipeline process for new board members by June 30, 2011.

**Objective 1.2:** Increase the size of the board to seven members by December 31, 2011.

**Objective 1.3:** Provide two to four opportunities (internal and external) for board members to participate in professional development/education programs by June 30, 2012.

**Objective 1.4:** Fill committee seats and launch committee activities by September 30, 2011.

**Objective 1.5:** Diversify board representation by recruiting younger board members and individuals from multiple ethnic communities.

### Goal 2: Transition appropriate programs from HTC to HSC

**Objective 2.1:** Create plan for transitioning programs by July 31, 2011 (including MOU, timing, funding, staffing and communications plan) from HTC to HSC.

**Objective 2.2:** Transition all selected programs to HSC by December 31, 2012.

### **Goal 3: Enhance programming offered to members and community at-large**

**Objective 3.1:** Assess member needs related to programming (i.e. population-focused programming, integrated bilingual/bicultural focus, how/when to offer programs) by October 31, 2011.

**Objective 3.2:** Research programs offered by other chapters around the country for ideas on how to enhance/improve existing programs and/or add new programs by October 31, 2011.

**Objective 3.3:** Utilizing assessment (Obj. 3.1) and research (Obj 3.2) findings, create program policies and procedures including: industry participation, volunteer policies, selection processes for summer camp, scholarships, etc. by December 31, 2011.

**Objective 3.4:** Determine which new programs are needed and create a plan for program design, launch and implementation by March 31, 2012.

### **Goal 4: Continue to improve and enhance organizational operations**

**Objective 4.1:** Hire an HSC program staff member by December 31, 2011.

**Objective 4.2:** Determine the role of consultants in implementing the strategic plan and ongoing operations; create plan with budget and timing of various consulting needs by in time for the 2012 board budget process.

**Objective 4.3:** Create an evaluation plan to measure outputs and outcomes, and tracking/analysis of each for programs, staff and volunteers by June 30, 2012.

### **Goal 5: Improve member communications and outreach**

**Objective 5.1:** Develop a strong member communications plan utilizing traditional and online communications strategies, including bilingual communications, by August 31, 2011.

**Objective 5.2:** Gather and share member stories—at least one member story per month—to be shared in the newsletter and/or through social media.

**Objective 5.3:** Create the infrastructure (staff or volunteer) and systems to respond to member and community inquiries and needs by June 30, 2011.

**Objective 5.4:** Set up meetings with individuals and groups (i.e. Western Slope, Hispanic/Latino community) around the state affected by bleeding disorders to strengthen relationships and inform programming.

## **Goal 6: Expand and diversify HSC funding**

**Objective 6.1:** Create and adopt a fundraising plan by August 31, 2011 (explore grants, industry and other corporate/business support, membership fees, program fees, individual donor program).

**Objective 6.2:** Develop and institute membership fee structure to launch January 1, 2012.

**Objective 6.3:** Provide board development and fundraising training to board members, appropriate committees and interested volunteers by December 31, 2011.

## Recommendations

A frequent concern during strategic planning is to end up with “just another plan sitting on a shelf.” Organizations that make their plan a “living document” that guides their work and changes as the environment changes employ some or all of the following techniques:

- ❑ Keep everyone who was involved in the planning process involved in implementing the plan. The more people engaged the higher chance of success.
- ❑ Provide board members with hard copies of *the plan* and make copies of the appendices available to them. The plan itself—the future business model and vision, goals, objectives and action plan—are essential. The additional pages of attachments can be available for review as needed.
- ❑ Provide staff members with hard copies of the plan and make copies of the appendices available to them. The organizational plan will be critical to staff as they develop their individual work plans and contribute to the overall implementation plan.
- ❑ As board committees are developed, have each committee create a work plan that ties to the overall strategic plan. Monthly/quarterly committee meetings should include time to discuss how that month’s committee activities supported achieving the plan goals and objectives.
- ❑ Add the action plan to the board’s agenda every month. Take 5-10 minutes to discuss progress toward achieving goals and objectives. Consider committee and staff updates to show how the plan is interwoven throughout the organization. Spend five minutes discussing obstacles and brainstorming how to overcome them.
- ❑ Consider creating a visual for the three-year vision. If you have an artistic person on the board or staff, ask them to draw your vision. Copy it, distribute it and post on the web site.
- ❑ Talk about the plan. Develop a common language by repeatedly referring to the vision, goals or objectives. Make the plan a part of everyday discussions and people will join in.
- ❑ Begin planning soon for the 20-month update to the action plan. With a three-year plan, one to two updates will be necessary before it’s time to begin again with a full strategic planning process. Schedule a half-day session to celebrate implementation successes, review and revise goals and objectives to achieve the future vision (if needed) and create a new action plan.

## Appendices

- A. Stakeholder Interview Report
- B. Member / Funder Survey Report
- C. Member Telephone Interview Report
- D. 20-Month Action Plan

## Appendix A: Stakeholder Interview Report

As part of the 2011 strategic planning process for the Hemophilia Society of Colorado (HSC), interSector Partners, L3C (iSP) conducted telephone interviews with key organizational stakeholders. The interview protocol was drafted by iSP and reviewed / approved by HSC leadership.

A request to participate in interviews was sent to 15 people based on a list provided to iSP by HSC. Six interviews were scheduled based on the initial request. Reminder emails were sent to those who did not respond to the first request yielding three additional interviews. A final email reminder yielded no additional interviews.

The following summarizes the interview protocol and responses from these nine interviews, each of which lasted between 20 and 40 minutes. All interviews were conducted by iSP principal partner, Caryn Capriccioso.

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**The following opening statements were reviewed with each interviewee prior to launching into the telephone interview.**

*This spring, the Hemophilia Society of Colorado's board of directors and staff are engaged in a strategic planning process designed to provide future vision, direction and strategy for the organization. The process includes an extensive stakeholder input from those closest to HSC including the board, staff, community partners, funders, advisors, clients and others familiar with HSC's work.*

*One part of this stakeholder input process is the telephone interview that you have been asked to participate in. Thank you for agreeing to be a part of this important process. Today's interview should take about 30 minutes. Your responses will be shared only in aggregate with other interview responses, so I encourage you to be as open and honest as you are comfortable being.*

*Do you have any questions before we get started?*

### Interview Questions and Summary Responses

Interviewees were asked to share their **affiliation with/relationship to HSC**.

- Three interviewees are employees of the Hemophilia Treatment Center (HTC)
- Two people indicated they are current board members
- Two stated they are former board members
- One each identified as a former employee and a consultant to HSC
- One person stated their affiliation as being a patient at the HTC

- Three people indicated they have a family member who has hemophilia or a bleeding disorder

Please note that the numbers do not total nine interviews, as several interviewees expressed their affiliation as being two-fold (for example, as a former board member and a family member of someone living with a bleeding disorder).

**Interviewees were asked to share their understanding of HSC's mission.** The majority of respondents identified at least a portion of the mission statement/mission correctly. HSC's mission reads as follows:

*The Hemophilia Society of Colorado is dedicated to enhancing the quality of life in the Rocky Mountain bleeding disorder community through advocacy, education, and emotional and financial support. This includes creating public awareness, promoting excellence in medical care, and providing a support network for individuals and families.*

Responses to this question included:

- In broad terms, it is to educate and support the hemophilia community and another part is to advocate
- To be patient advocates
- To put hemophilia health care to the forefront
- To advocate for families and patients with hemophilia in helping them achieve a better quality of life through education and financial assistance
- Serve as a resource and an advocate for families and patients who are dealing with bleeding disorders
- To advocate and bring awareness to the bleeding disorder community within Colorado
- The community-based organization of both patients and families dealing with bleeding disorders to help educate the community about the disease/disorder and provide support through educational programs
- To provide support, education and networking to support the hemophilia and bleeding community in Colorado
- To provide legal and personal advice

**Responses varied when interviewees were asked how well they believed that HSC is currently doing at achieving its mission.** Most did agree that there is work to be done, but that things are on a good track. Responses included:

*“Ever since our new ED came on full-time, I think it’s going really well.”*

- Headed in a positive direction
- Huge lag time for the community to catch on to how well we’re achieving the mission
- Undergoing tremendous growth and heading in a positive direction
- Much better than two years ago
- We are starting all over again

Two people expressed concern about how strongly the mission is being met today:

*“I guess I’m not very comfortable with it. By trade, I am fairly detail oriented and I haven’t seen a lot of detail as to what we’ve done. I also see a lack of process / procedures to handle certain events that come up.”*

*“They haven’t necessarily met the mission in the last few years.”*

And one person indicated they would like to see the mission expanded:

*“Well, it’s not in the mission, but I’d like to see us add research. So we’re achieving the current mission, but I see a broader mission.”*

**Interviewees were then asked to describe what it is that they believe makes HSC most valuable to the community as a whole.** Visibility and awareness for hemophilia and bleeding disorders were the most common responses.

*“It’s a marvelous way to spread awareness about hemophilia, what it is, dispel myths.”*

*“The education and information they provide regarding hemophilia.”*

*“I think it’s extremely important to help the community know the difference between the chapter and the treatment center.”*

**Next, the question focused more directly on people living with bleeding disorders and hemophilia asking interviewees to identify what makes HSC most valuable to this group.** Answers provided more than once include the total count in parentheses following the response.

- Education and information services (5)
- Social interaction/forum for families and people with bleeding disorders (5)
- Financial support (2)
- Emotional ties. People have been with us for years.
- That the organization is run by people who are affected
- Communication with patients and the treatment center
- Links to community resources
- Camp
- Events
- Advocacy

*“When you’re tapped into HSC, you have a stream of information, a way to tap into people who are dealing with the same set of concerns and challenges.”*

*“It’s great to be part of something that’s working to solve the problem and that brings hope to people.”*

**Interviewees had a number of ideas for where HSC could improve. Responses are categorized below:**

#### **Programs**

- HSC could take programs back from HTC
- Focus more on teenagers, women and older men
- Prioritize our programming; figure out what we’ll offer, what HTC will offer and what’s needed
- Provide more opportunities to get people together
- Workshops that meet the needs of various populations like new parents, parents learning about ports or how to get on home therapy
- It’s so important to keep camp in place
- Take a more active role in running camp

### **Funding**

- Better fundraising by accessing the world beyond our current supporters
- Need more foundation support
- The board needs to give money; especially those who have the resources

### **Communication/Positioning**

- Expand beyond our circle of affected families and tie bleeding disorders into the larger health disparities conversation
- Communication and outreach to members; it's been inconsistent

### **Board of directors**

- Need strong management on the board. Put organization, not selves, first.

### **Policy/advocacy**

- Dive into public policy and how it relates to hemophilia in Colorado

### **General**

- Getting organized in terms of timetables, schedules, financials, etc.

**Next, people were asked to talk about any external threats they believed to be present.** Many interviewees described internal challenges in addition to threats and those challenges are included here, as well.

### **External threats**

- Merging with national could cause us to lose autonomy
- Industry folks trying to use HSC to target clients
- Lack of awareness and visibility about the chapter
- Lack of awareness and understanding of bleeding disorders
- Changing nature of the disorder; people are healthier and living longer making it harder to build a case for support
- Fear/lack of understanding of hemophilia and the perception that it is tied to AIDS
- Cutbacks to state funding that supports HTC
- Homecare companies competing with HTC
- National Hemophilia Society is a large corporation; that could feel threatening
- A rapidly changing industry (mergers, consolidations, health care reform) and lack of understanding of how to adapt
- Patient choice is diminishing

*“The biggest threats come from outside the organization, and within our own community. There are a lot of people mad at The Society. It’s people that have worked at the society in the past. It’s surfacing now.”*

### **Internal challenges**

- Self-interest focused: self, family, industry. People don’t think of the organization as a whole
- Sense of entitlement
- By virtue of being small, HSC is vulnerable to personalities that can alienate some people
- People do not choose to share this common interest making for very diverse interests— political ideology, socioeconomic interests, etc. (This was also identified as a potential strength: having a broad spectrum of people represented.)
- The propensity for chapters to rely 100% on industry funding.
- Our new executive director might try to do what is common or expected at other nonprofits without understanding the dynamics at play here

*“Medicine is better than it’s ever been. Life is better but still hard and very, very expensive. Access to health care is still a challenge, but there’s so much more that people can do at home. Life is better for most people living with a bleeding disorder. They are no longer crippled by age 15. But, this situation means that fewer people show up to events, they don’t need HSC as much as they used to. We need to ask ‘What is it to be relevant today?’ ‘What will make a difference in their lives today?’”*

*“I don’t see external threats. I see our biggest challenge is burnout. The board members are burned out. I don’t see enthusiasm. We need to get people involved so that they are enthused. Or, give them a break, and let them recharge.”*

### **When asked “what opportunities do you see on the horizon for HSC?” responses varied:**

- Find common ground with other health issue organizations and work together
- Research and cure activities
- Improving on the walk, building on positive momentum
- Advocacy with legislators for the funding stream. It’s something right here at home that we could band together to work on.
- Industry relations and funding could be even better
- Board members who can focus on what’s best for the organization and the people living with hemophilia
- Advocacy, public policy, and legislation
- A patients’ bill of rights and state funding

- Attending Washington Days; with a budget for this and members who are excited about going
- Training in advocacy for families; people don't get how important it is, they don't know how to do it
- Emily is doing a great job; keeping her is an opportunity
- Education days quarterly
- Holding shorter meetings with specific topics to create the habit of getting involved with the community.
- Get industry to support an expanded education program
- Need an agenda ahead of time for the education day. Then people can plan what they want to go to.
- Western Slope division could participate in these shorter term education programs
- More support groups
- Transitioning the major governance tasks to national will free up the advisory board to focus on advising on strong programs and making choices for the community.
- Opening up the door to new funding sources, especially new individual donor development
- A women's program would be huge. There's a whole population that is not being directly addressed.

**iSP asked people to share their vision for what HSC could be doing in five years.** The following are verbatim responses with slight adjustments to maintain response anonymity.

- ❖ Continuing to help people living with hemophilia and their families
- ❖ More communication regarding the education and more of the networking opportunities. I know from my [family members'] perspective, they have been so grateful to HTC and HSC for parents educating parents program (PEP) where they got to meet other parents dealing with hemophilia to learn and establish good bonds.
- ❖ Make sure that people can get registered and participate even if they don't have computers. A lot of people are lower income and don't have access; they need to feel invited, included and wanted.
- ❖ Helping children through the summer camp. We will take the summer camp back and share with HTC rather than having HTC do everything.

- ❖ We'll offer new programs for underserved populations and constantly evaluate what that means
- ❖ I'd like to see our board bring in more money. We're on a tight budget and are somewhat constrained by the budget. We need to expand the board with the focus on those who will be open to fundraising.
- ❖ Again, research and cure activities
- ❖ Have strong equal partnership with HTC and stronger educational/community presence.
- ❖ The cause needs a spokesperson. So, in ten years, people would know about it.
- ❖ Have fully bilingual materials and programming. Create programming that is welcoming and reaches a little deeper to reach the families.
- ❖ Create role models or mentors for families. For instance, pair young adults with families who have kids with hemophilia so that families can learn more about the challenges their children will face as they get older.
- ❖ We'll be under national. I see a local advocacy team that would actively provide support and give consultation to others, too.
- ❖ Better subsidized, trained and managed advocacy team
- ❖ A second staff person to do fundraising. The executive director can't do it all.
- ❖ Scheduled quality training for each board member. Learn what they need to know and help them get the training they need.
- ❖ Good communication on many different levels
- ❖ Serving as feeder to the national group with both upstream and downstream communications
- ❖ A diverse range of activities, events and opportunities

- ❖ Very strong, clear conflict of interest focus to keep industry in check. We will eliminate direct-to-consumer marketing and trying to get customers through buying them dinners, etc.
- ❖ Stronger financial assistance
- ❖ Advocacy & lobbying

**The following questions were asked of board members only.**

**When making decisions on behalf of HSC, what are the top things you take into consideration?**

- Approvals from nurses, social workers, docs, etc.
- What the community wants
- The people
- Long-term benefit to the organization and the members; not a one-shot deal
- We are about as low as we can get in terms of enthusiasm; would need to have people enthused
- Live within our means, so is this within our means?
- Can we afford it?

**What are your top three priorities for your new executive director in the next year?**

- Fundraising
- Take over 100% of the programs away from the treatment center
- Move the program coordinator to HSC from HTC
- Continue to establish her leadership as executive director
- Rally the positive energy
- Start to take the programs on
- Focus on fundraising – not that she does it all, but help us learn how to approach people
- Delegate: bring more people into the organization and get them engaged; need to follow-up with people when they offer to help. Key volunteers get-together to figure out who the “super volunteers” might be.
- Looking at bi-cultural opportunities (bilingual is good, but bicultural is better). We can’t just have translators; we need to have people who represent the communities.

*“What she’s done already would have been my priorities. She is doing great. Keep getting things organized and stable and plan for 2012 priorities.”*

## Appendix B: Member / Funder Survey Report

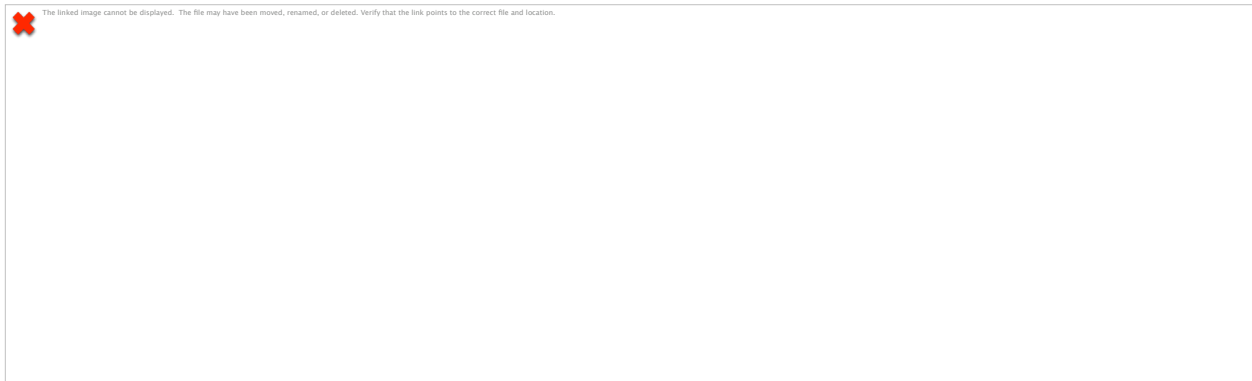
As part of the 2011 strategic planning process for the Hemophilia Society of Colorado (HSC), interSector Partners, L3C (iSP) administered a survey to key stakeholders including community members, medical service providers, funders, sponsors, collaborators, and other community partners. The survey was drafted by iSP and reviewed / approved by Emily Davis.

The survey was sent with an email invitation to 144 stakeholders on Friday, April 1, 2011. Three reminder emails were delivered to encourage participation. When the survey closed on April 12, 2011, 29 people had completed their survey.

The raw survey responses are provided below. Please note that some typos and misspellings were corrected for ease of reading, but no significant corrections were made to ensure the integrity of the responses.

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### Please choose the option that best describes your connection to HSC:



Value	Count	Percent %
Community member (individual or family member affected by a bleeding disorder)	22	75.9%
Medical services provider (i.e. treatment center staff, hematologist, etc.)	1	3.4%
Funder / sponsor/collaborator/community partner (i.e. pharmaceutical company, home care company, community foundation, etc.)	6	20.7%

Statistics	
Total Responses	29

## What is your understanding of HSC's mission? Please share what you believe to be the HSC mission in the space below:

### Response

Educate, support and advocate for the bleeding disorder community.

I do not know the mission statement.

Provide education and support

To assist and be advocates for those in the bleeding disorder community.

To educate and advocate for the bleeding community

To educate and inform about hemophilia and other bleeding disorders.

To help people and their families with bleeding disorders.

To help support and education people with and about bleeding disorders

To provide support and encouragement to the hemophilia community.

To support members of the hemophilia community

To support, bring together, and advocate for those affected by bleeding disorders.

educate people re bleeding disorders

education and services for the bleeding disorders community

To support, educate, and network the bleeding community of Colorado through a variety of programs geared toward young families, parents, and affected adults.

I think the HSC is currently developing its mission more clearly, as I think it has been unclear to the community what its role is in support/resources, etc...to the CO hemophilia community. I do not know its current mission off the top of my head, but would imagine it is to develop resources, supports, assistance, information, etc... for the community

To enhance the quality of life in the bleeding disorders community through advocacy, education, emotional and financial support and to increase public awareness.

To advocate for, educate and help out when necessary people living in CO with bleeding disorders.

To provide services and programs to members of the bleeding disorder community in Colorado, including advocacy, education, and support.

To act as a resource to families and individuals affected with hemophilia by providing resources, advocacy, and increasing awareness of this disease.

The society exists to advocate for and educate people with bleeding disorders. The Society will also educate the general public about bleeding disorders.

The mission of the HSC is to provide support, education, outreach to members of the community who are affected directly by a bleeding disorder or who have a family member affected by a bleeding disorder.

Don't know that I know exactly but basically to educate and give support to the bleeding order community of Colorado and surrounding areas.

## Response

### What is your understanding of HSC's mission? (continued)

Provide patient support to better the lives of bleeding disorder patients in a stated geographical area.

To assist members (and their families) with guidance, opportunities for networking, making relationships and general knowledge about how to take care of their medical condition

Support the community through education, collaboration, networking and emergency financial support.

To provide education, networking opportunities and advocacy for the Colorado bleeding disorders community

To promote education, connect families, and raise money for special programs to the benefit of individuals and families affected by hemophilia.

Providing resources to the hemophilia community to help improve patients' quality of life. Advocating for patients rights with appropriate stakeholders. Protecting the community's interests regarding access to, and quality of, clinical care.

Educate, advocate and assist patients and families with bleeding disorders, along with community education and political advocacy.

### How well do you believe HSC is doing in achieving its mission?



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Value	Count	Percent %
Not well	1	3.4%
Not very well	2	6.9%
Neutral	13	44.8%
Well	7	24.1%
Very Well	3	10.3%
Not sure	3	10.3%

#### Statistics

Total Responses

29

## HSC Strengths:

- Ability to overcome obstacles that have threatened the existence of the organization
- Camp
- Communication (content)
- Communication (only recently)
- Dedicated Personnel
- Education
- Education material
- Educational Events
- Emily
- Have been very proactive of late trying to recruit board members
- I would have no idea
- New Executive Director
- New leadership and energy
- Outreach
- Strong executive director in place
- The members
- advocacy
- dedicated people
- getting organized currently - finally
- great people
- members are wanting to stay together
- not sure
- organizing functions
- outreach to hemophilia families
- personal bonds with the community
- recent involvement of young leadership
- sounds like we have some capable bodies now
- support for research
- Advocacy
- Continue to educate patients thru various programs
- Emily
- Improved communication at all levels
- New Executive Director seems to be working hard on improving the organization
- New Policies in Place
- Programs
- Purpose/intentions
- Semi-functional Board
- Strong history
- Supporting Families
- The new director
- a lot of heart
- desire for change
- education
- having persons with hemophilia on the board
- not sure
- recent NHF partnership
- small and flexible
- strong community base
- support
- support for families
- Community network
- Emily
- Good events
- Recent partnership with NHF
- Relationship with HTC
- Relationship with Medic Alert foundation
- Shared vision and accountability is emerging
- Support of Industry and HTC
- The partnerships in the community
- The support of the HTC has been crucial in HSC's survival.
- care of members
- community
- facilitate community interaction
- not sure
- partnership with HTC
- some excellent community events
- the new executive director
- willingness to develop connections to the community

## HSC Weaknesses:

- lack of boardmanship training and strategic plan
- Adjusting to the changes
- Board needs to get organized
- Communication
- Communication (frequency and quality)
- Communication - but seeing this improved already
- It is still hard to see the HSC as a viable organization with funds to support and educate
- More visibility in the public
- Need outreach to rural areas - instead of Denver-based activities
- Need to broaden participation to community members
- No overall game plan
- Outreach to members
- Uncertainty re. the mission of the HSC
- communication
- controlling board members
- disorganization of past
- disorganized
- expand interested community members
- few people outside of the community
- history of negative internal stresses
- lack of widely accessible events
- more ways to help families connect
- negative political advocacy
- not sure (x 3 responses)
- overall presence in the community at large
- pulling the community together
- turnovers in HSC
- Clarity
- Diversified fundraising
- Family events
- No overall vision for industry partners
- Organizational structure
- Returning calls
- Setting goals and communication on if/how they are being met
- Timeliness of mailings
- ability to partner with other organizations
- communication with members, is improving
- lack of marketing
- lack of structure
- lack of widely accessible services
- need more people involved
- no clear plan for the future
- people don't get along
- poor communication
- provide more educational opportunities throughout the year
- some burn out amongst current board and previous board members
- Board recruitment
- For industry, cost versus benefit analysis is becoming murkier and more difficult to define
- Lack of a network outside of the hemophilia community
- Organization
- Relationships with medical community
- Visibility
- Volunteer involvement
- ability to obtain grants and donations
- better fundraising & brand materials
- dropping the ball
- geographic challenges - isolated rural communities
- lack of community involvement which started two years ago with a certain community member
- lack of smaller educational events rather than only big events
- make things fun for community
- needs improved marketing /visibility
- unwillingness to listen to all

**Community members: do you participate in any of the following HSC programs or activities?**

	<b>Yes</b>	<b>No</b>	<b>Not Sure</b>	<b>Total</b>
<b>Education Day</b>	<b>63.6%</b> 14	<b>27.3%</b> 6	<b>9.1%</b> 2	<b>100%</b> 22
<b>Financial Assistance Program</b>	<b>9.1%</b> 2	<b>77.3%</b> 17	<b>13.6%</b> 3	<b>100%</b> 22
<b>Advocacy (Washington Days)</b>	<b>9.1%</b> 2	<b>90.9%</b> 20	<b>0.0%</b> 0	<b>100%</b> 22
<b>Academic Scholarship Program</b>	<b>4.5%</b> 1	<b>90.9%</b> 20	<b>4.5%</b> 1	<b>100%</b> 22
<b>Women's Retreat</b>	<b>9.1%</b> 2	<b>86.4%</b> 19	<b>4.5%</b> 1	<b>100%</b> 22
<b>Mile High Summer Camp</b>	<b>45.5%</b> 10	<b>50.0%</b> 11	<b>4.5%</b> 1	<b>100%</b> 22
<b>Hispanic Programming</b>	<b>4.5%</b> 1	<b>95.5%</b> 21	<b>0.0%</b> 0	<b>100%</b> 22

## Community members: what is the best thing that HSC has done for you or your family?

### Response

Camp, Ed days, and PEP

Education at PEP and Education Day

Family Camp and partner with the HTC in providing valuable services to those with hemophilia

Helped us meet other families in similar situations!

Helped us to connect with people who share similar experiences in dealing with hemophilia.

It has provided networks to other families within the community.

Nothing yet.

Participation in Washington Days.

camp

keeping us in the loop even though we can't attend many things

not anything that I can recall at the moment

Connected us with other families of children with bleeding disorders and given us opportunities to interact.

The summer camps for both of my sons were tremendously helpful. Also the society has been a huge support to my younger son who is currently a resident at CU medical school in pediatrics.

## What is the best thing that HSC has done for you or your family? (continued)

It has changed.... I feel, not as welcomed or I guess "the stranger" now. But in past years I have felt very supported.

Provided a resource for me to get information and connect with other parents dealing with a bleeding disorder.

Provided education and networking opportunities with other affected families. I have assisted with a variety of programs over the past 33 years, most recently organizing workshops, the walk, and meetings on the west slope.

Family camp and education day, kid's camp. I just know that other foundations around the country offer so many more opportunities to get together and support each other.

Get my partner more in contact with resources and information, let him meet other people with hemophilia and become more comfortable with himself, provide us with educational opportunities we didn't know existed before

Initially, First Steps was very helpful. Any and all of the education workshops have been extremely helpful (although we have been yet able to attend Education Day). We have yet to make it to Education day and this is our first year for camp but I think both are wonderful to opportunities to be further educated and connected in the community.

Education Day - bringing all the resources together in one place and making it easy to learn more. Social events like the picnic - having the opportunity to meet families with hemophilia

When my son was younger, he participated in the camps which were a great experience. I used to volunteer regularly and edited Cascade Magazine for the society.

1st steps were amazing when we became community members. We learned so much at a time when we were so scared.

**Community members: as HSC works to ensure that the organization is stable and strong into the future, it is exploring the costs of providing some programs and services. How likely would you be willing to pay a small annual membership fee to participate in HSC programs and / or services?**

<b>Value</b>	<b>Count</b>	<b>Percent %</b>
Very likely	8	36.4%
likely	5	22.7%
neutral	5	22.7%
not very likely	1	4.5%
not at all likely	2	9.1%
not sure / not applicable	1	4.5%

<b>Statistics</b>	
Total Responses	22

## **Community members: please share any thoughts you have about paying an annual membership fee to participate in HSC programs / services.**

### **Response**

I am comfortable paying an annual membership fee.

I am moving, however I may consider if more information about the scope and depth of programs.

I think it would depend on what services were offered.

It would depend on the fee and service. Already paid to become a lifetime member of HSC.

It would depend on the services.

It's something I'd need to think about before I commit.

Other organizations do so it would not be a problem.

Perhaps if there is a membership fee, more people will participate in events and activities.

no problem

It would need to be very affordable for the community at large, as families come from a huge variety of resource backgrounds and would hate to see people not access resources because it was only offered as a cost

The availability of services and programs, and the likelihood that they will fit into my schedule, is too low for me to invest money at this time.

Not opposed to it, but I would like to see more details about how the money is actually spent...that has not been clear in the past.

I would like resources to be available for free for everyone or people just learning. But I would be ok paying a fee to participate in events and activities.

Our family has been fortunate enough and we have good insurance so a small fee wouldn't be a big deal but I don't know if that's the case for the vast majority. I think a fee would prohibit some families for partaking.

### **Please share any thoughts you have about paying an annual membership fee to participate in HSC programs / services. (continued)**

We originally paid for the Lifetime Membership option which I believe was \$200 because we believed in the benefits that being connected and educated had for us and our child (now children).

Programs change, so I would be up for paying. However, I would like to know first about all the years' events.

my concern would be directly related to the funding of any political advocacy efforts by HSC. I am very disturbed by HSC support for Obama care - the relatively minor help for the hemophilia community could have been achieved in many other ways, without cutting Medicare by \$500B and socializing medical care.

My one question is for those people who have paid already for a lifetime membership, would that be rolled over to this?

I feel that membership fees are a normal and expected part of sustaining any organization. They

## Response

can be tiered to be very affordable.

as long as people who need the services are not prevented from getting them due to cost, i.e. scholarships

I would only be happy to pay a membership fee if there were greater transparency into what the HSC does, how they help the community, where the money goes, etc.

My family has raised over \$65,000 for the society and we were told that we had a lifetime membership, if that happened and they didn't honor that we would be upset.

## Would you be willing to pay for an annual family membership?

	<b>Value</b>	<b>Count</b>	<b>Percent %</b>
	\$15	2	9.1%
	\$25	10	45.5%
	\$50	4	18.2%
	\$100	4	18.2%
	I would not be willing to pay a membership fee	2	9.1%
<b>Statistics</b>			
	Total Responses		22

## **Community members: please share your thoughts about why you would not be willing to pay an annual membership fee.**

### **Response**

see above

See above. We were told we had a lifetime membership as a way of saying thank you for all of the fund raising our family did. Just because there may be new people on the board now, doesn't mean that should not be honored.

## **Community members: is there anything that HSC could do differently that might change your mind about paying an annual membership fee?**

### **Response**

no

This is a bad time for most families to be thinking about adding expenses to our budgets. Beyond this, I might change my mind if the gatherings and services were more frequent and accessible in my community and on my schedule.

## **Funders: why do you contribute to/support HSC?**

### **Response**

To help the community

to benefit the community

Industry, in particular biotech companies should support a patient centric organization that can help alleviate the concerns of patients that live with chronic diseases

HSC supports people with bleeding disorders living in a vast geographical area. Not everyone has close access to the Denver based HTC and even those who do, need education and resources.

I want to see the individual members of the HSC living well, and I want to see the group thrive as an organization.

I have come to appreciate the families and individuals in this community and wish to support them and their needs.

## Funders: do you feel your support of HSC provides good value to your company or organization?

Value	Count	Percent %
Yes	4	66.7%
Not Sure	2	33.3%

Statistics	
Total Responses	6

## Funders: please describe activities that provide the best value to your company or organization.

### Response

Educational programs

Activities that allow a sole sponsorship environment that under a "controlled" system can bring visibility of manufacturers products and services

Opportunities to share time with families and individuals (family camp, education day, Black and Blue, golf tournament, education programs, etc)

Our goal is to make sure that every state in the US has support and resources for those with bleeding disorders. We absolutely need and value the work that HSC does.

## Funders: what ideas do you have for how your HSC support or sponsorship could create more value?

### Response

not sure what you mean

Get community members to attend the events. There has not been much turnout lately to education day, etc.

## To what degree do you agree with the following statements?

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not Applicable/Not sure	Total
HSC has well-developed community partnerships	3.4% 1	17.2% 5	44.8% 13	10.3% 3	0.0% 0	24.1% 7	100% 29
HSC brings value to partner relationships	0.0% 0	41.4% 12	37.9% 11	3.4% 1	0.0% 0	17.2% 5	100% 29
I can name three HSC community partners	13.8% 4	10.3% 3	20.7% 6	34.5% 10	17.2% 5	3.4% 1	100% 29
Community awareness of HSC is high	0.0% 0	13.8% 4	27.6% 8	34.5% 10	17.2% 5	6.9% 2	100% 29
I would recommend HSC to a friend or family member	17.2% 5	48.3% 14	31.0% 9	3.4% 1	0.0% 0	0.0% 0	100% 29
HSC's marketing is strong	0.0% 0	6.9% 2	31.0% 9	44.8% 13	13.8% 4	3.4% 1	100% 29
HSC's financial management is strong	0.0% 0	13.8% 4	27.6% 8	24.1% 7	13.8% 4	20.7% 6	100% 29
HSC's administrative functions are strong	3.4% 1	13.8% 4	37.9% 11	17.2% 5	3.4% 1	24.1% 7	100% 29
HSC's leadership functions are strong	6.9% 2	17.2% 5	44.8% 13	20.7% 6	0.0% 0	10.3% 3	100% 29
HSC's volunteer engagement is strong	0.0% 0	13.8% 4	31.0% 9	31.0% 9	10.3% 3	13.8% 4	100% 29
HSC's communication with the community is strong	3.4% 1	31.0% 9	37.9% 11	20.7% 6	6.9% 2	0.0% 0	100% 29
HSC is an inclusive organization (i.e. diverse in age, skills, ethnicity, etc.)	17.2% 5	41.4% 12	17.2% 5	6.9% 2	0.0% 0	17.2% 5	100% 29
I understand the bleeding disorder field	41.4% 12	44.8% 13	10.3% 3	3.4% 1	0.0% 0	0.0% 0	100% 29
I would like to know more about bleeding disorders	6.9% 2	27.6% 8	34.5% 10	17.2% 5	10.3% 3	3.4% 1	100% 29
HSC offers value to the community	20.7% 6	55.2% 16	24.1% 7	0.0% 0	0.0% 0	0.0% 0	100% 29
I know who HSC's community members are	3.4% 1	31.0% 9	44.8% 13	3.4% 1	13.8% 4	3.4% 1	100% 29

## To what degree do you agree with the following statements related to HSC's programming?

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not Applicable/Not sure	Total
HSC's programming is effective	0.0% 0	34.5% 10	41.4% 12	13.8% 4	6.9% 2	3.4% 1	100% 29
I am familiar with HSC's Education Day	31.0% 9	55.2% 16	3.4% 1	6.9% 2	0.0% 0	3.4% 1	100% 29
I am familiar with the Financial Assistance Program	3.4% 1	31.0% 9	17.2% 5	24.1% 7	10.3% 3	13.8% 4	100% 29
I am familiar with HSC's advocacy programs (i.e. Washington Days, Colorado legislative work)	10.3% 3	51.7% 15	27.6% 8	10.3% 3	0.0% 0	0.0% 0	100% 29
I am familiar with the Mile High Summer Camp	31.0% 9	51.7% 15	13.8% 4	3.4% 1	0.0% 0	0.0% 0	100% 29
I am familiar with HSC's Academic Scholarship Program	10.3% 3	37.9% 11	34.5% 10	6.9% 2	3.4% 1	6.9% 2	100% 29
I am familiar with HSC's Women's Retreat	3.4% 1	41.4% 12	31.0% 9	13.8% 4	0.0% 0	10.3% 3	100% 29
I believe HSC offers the "right mix" of programming	0.0% 0	20.7% 6	65.5% 19	13.8% 4	0.0% 0	0.0% 0	100% 29
HSC duplicates efforts of other community nonprofits	0.0% 0	0.0% 0	31.0% 9	31.0% 9	20.7% 6	17.2% 5	100% 29
I trust HSC to select the proper service/program mix	3.4% 1	34.5% 10	51.7% 15	3.4% 1	6.9% 2	0.0% 0	100% 29

**Please share your vision of what HSC will look like  
(i.e. size, scope, programming, partnerships, funding)  
on December 31, 2013**

**Response**

?

A few fundraisers each year, a way for members connect with one another

Clear mission, great resource for hemophilia info and support, strong regular funding base

I have no idea. That should be the vision of the Board of Directors and the Executive Director.

I'm not sure what I want it to look like.

More community involvement, family camp will return, more community dinners, education

N/a

Not sure

Strong community support with great turnout for events from engaged stakeholders.

balance of advocacy, fun, education

more accessible programming

more people on the board with more financial outreach enabling more educational programs.

not sure

not sure--but better than it is now

not sure...

Families and individuals with bleeding disorders will embrace the HSC as an invaluable resource. They will understand the work and programs the HSC puts on and will know how those items help the community. They will want to volunteer because they know how much it has helped them and want to pay that forward.

I would like to see a strong and active board, with folks who have the potential to contribute and who are not necessarily affected by a bleeding disorder. I would like to see more programs connecting our youth and the families. I hope we have solid funding.

I'd like to know where you stand, as a very active volunteer for many years, who gave up trying to work with HSC due to the extremely poor leadership of your Executive Director(s) it became too difficult.

larger, more involved board more connected to the community (hemo & at large), programming focusing more on smaller events, services to specific areas/communities around CO rather than just big events focus, partnerships with a variety of organizations, not just manufacturers, where HSC dictates what it wants in programming, not relying on manufacturers to dictate programming, financially secure

HSC will provide continued education to the community, will follow and share research, will raise money, and will support all members of the community.

HSC has the organizational capacity to provide stable, positive leadership, programs, and services to the bleeding community that is a model nation-wide

## Response

I am not sure what it would look like-my children are grown, I would assume it would have a large education component and definitely continue with the summer camp.

### **Please share your vision of what HSC will look like (i.e. size, scope, programming, partnerships, funding) on December 31, 2013. (continued)**

HSC will be the leading partner in the programs offered. Significantly increased volunteers and visibility in the community.

continued connectivity of state with programs offered for both regions, not just on the front range

The organization appears to have turned the corner. Unfortunately the onslaught of healthcare reform has changed the dynamics. The larger industry partners may not be as viable in the near future, so funding will be at risk. The organization will need to look outside of industry to help secure their future

HSC will have a diversified funding base, new board members added to current board, greater Colorado community outreach (not just bleeding disorder), three staff members, and outreach programs throughout state.

Having consistently, fun and educational programming that keep people wanting to come back. When we 1st started with the community 4 years ago we had lots of opportunities to meet with other families and learn and just visit. I'd like to see more of that.

A board that is more functional and WORKS on their projects Return of family camp and golf tournament.

Communication is a key for me and I have seen a huge improvement since the beginning of the year. I am delighted by that and hope for it to continue as it is making me more aware of what HSC is doing.

### **HSC is in the process of becoming a merged chapter with the National Hemophilia Foundation (NHF). What concerns or feedback do you have for the chapter merging with NHF?**

## Response

Concerned that we will lose our flexibility and ability to react quickly to needs.

I just hope we still have the autonomy we need to service specific needs in Colorado.

I think it's a good idea.

Keep the local interests in mind.

N/a

No concerns at all.

No concerns. I'm very excited about this merger.

None really

None, I think it is an excellent idea and opportunity.

None.

## Response

Not sure

Not sure still if this is good or bad, not much communication about this

hopefully trust

### **HSC is in the process of becoming a merged chapter with the National Hemophilia Foundation (NHF). What concerns or feedback do you have for the chapter merging with NHF? (continued)**

it can only help

none

stay micro w your focus on local members - a good idea!

The HSC will have to ramp up their ability to increase funding into the organization to survive and pay staff. Industry is always concerned that they will be priced out. The merger to the NHF should help, but that remains to be seen. A final report card will take a few years to play out.

My concern is that in-state funders want to be assured their dollars remain in-state. I believe such a mechanism will be in-place.

that political advocacy would be more restrained and focused in the future, and that all advocacy efforts in support of Obama care would cease

At previous meetings everyone has alluded to some kind of issues or drama but it really hasn't been clear.

What will NHF force the HSC to do? Do the benefits of being affiliated with the NHF outweigh the negatives?

Merging with NHF will help HSC achieve a national viewpoint regarding patients with bleeding disorders, offer increased resources -- the primary focus of HSC needs to remain at the local level.

The NHF is struggling for relevancy, and undermined by mistrust and scandal...partnering with them holds very few advantages.

I think that would be fine, it couldn't be any more poorly run than it has been in the past several years.

loss of connectedness due to being under the larger umbrella; western slope people once again being left out

I don't want to lose our individual connections with local member when we merge to a National organization.

I think collaboration can be a great option for struggling nonprofits and others with whom overlap and/or common ground occur.

I think it is a good connection, not sure how it will eventually impact how HSC runs, but current support from national is allowing it to get more organized now

**As HSC transitions to a more formalized relationship with the National Hemophilia Foundation, it plans to work with an advisory board to provide input and ideas to HSC. What do you think the board's role should be in guiding and/or advising the organization? (i.e. managing administrative duties, deciding on programming, raising money, supporting members, etc.)**

**Response**

I feel too uninformed to answer this question

Managing and directing programs.

Not sure

Not sure. I don't know that I could answer this adequately.

Not sure...who would make up the advisory board?

Programming, raising money, supporting members

Provide ideas for raising money and handling of administrative duties.

Raising money, supporting the Executive Director, and furthering the mission of the organization.

all

don' know enough about roles to make a judgment

don't know

guiding

n/a

programming and supporting members

programming, fund raising, communication

programming

support of research efforts and community interaction

the two need to interdependent-and share with each other all of the above.

I believe that the advisory board should be primarily focused on fundraising, programming, and member support.

NHF needs new leadership...that people can trust. It needs to find ways to listen to, and support local chapters, rather than compete with them for funding and programming.

The Advisory Board is a good idea in helping the organization decide on programming for the upcoming year. Although they should not be making any decisions. If an advisory board member wants to volunteer their own time, fine, but it should not be a requirement. If so, change the name from the Advisory Board to something that reflects the true nature of their responsibilities.

**As HSC transitions to a more formalized relationship with the National Hemophilia Foundation, it plans to work with an advisory board to provide input and ideas to HSC. What do you think the board's role should be in guiding and/or advising the organization? (i.e. managing administrative duties, deciding on programming, raising money, supporting members, etc.) (continued)**

the board should be involved as the major governing body of all events, programming, etc...connected to HSC - making committees to oversee things for efficiency and so all doesn't have to go through the board would work more smoothly. I think recruiting expert volunteers or board members in terms of educational programming, medical background, fundraising, connection/support to community would be beneficial

I think they should make sure things are running smoothly on the board and with the funds but they should also listen to what the local needs are and let the HSC continue to help the people in our community.

The advisory board should ensure that the HSC is working to achieve its mission, but not micromanage.

I would hope that NHF wouldn't be making all the decisions but would allow HSC to have a strong voice in the needs of its members

The advisory board should have an important voice in bringing Colorado based issues to the table and working collaboratively with NHF to tailor make strategies that are mutually beneficial. decide programming priorities review administrative performance fund-raise allocate member support

I think the Advisory Board should function similarly to the current governing Board of Directors - with NHF having fiduciary responsibility. HSC should determine which programs make sense for its members. HSC should work with NHF to determine managing administrative duties, and raise money locally to be kept locally for its work/mission.

You can have too many or too few committees, too many or too few meetings that you lose effectiveness. The board's role in guiding/advising the organization should be a partnership that first serves the HSC at the local level and then NHF. Right now HSC focus needs to be on nurturing the strong local roots that have been planted.

Don't really understand the question. Why do you plan to work through and advisory board if you don't know what you want that board to advise upon? I'm confused with this one. Sorry.

## Appendix C: Member Telephone Interview Report

The Hemophilia Society of Colorado (HSC) had hoped to conduct a focus group with members to take a deeper dive into responses from its Spring 2011 strategic planning survey. Unfortunately, interest in attending the focus group was low and the meeting was not held. interSector Partners, L3C and HSC executive director, Emily Davis, decided to follow-up with interested parties by telephone.

Three people participated in follow-up calls to the survey. The following summarizes the responses from the member phone calls. All interviews were conducted by iSP principal partner, Caryn Capriccioso.

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### Interview Questions and Summary Responses

#### *Please share your affiliation with HSC.*

All three interviewees have children with hemophilia. One interviewee has a child with hemophilia who is now a young adult, living away at school.

#### *Which HSC programs do you or your family participate in?*

- For many years, my child went to camp. We're big fans of the camp.
- We used to do ski trips
- We volunteered and participated in the golf tournament
- The Walk
- Washington Days
- I hope to be involved in the advocacy committee
- Two people indicated they attend the holiday party

#### *You will recall that a few questions on the survey focused on the potential of a small membership fee. What are your thoughts on this option?*

We would be willing to pay a membership fee. It would help to know exactly where that money was going. Sometimes we don't even hear about the events, so we'd want to be sure to know about the benefits to members and all of the events if I pay.

Many years ago, HSC would ask for a donation to get access to information about events and activities. Then the voluntary membership fee just went away. Membership allowed you to get the newsletter, membership directory (shared with permission) and some other things.

This is an extremely expensive disease, but it's also isolating. If there is a small cost to have the opportunity to be part of something, that can't be overlooked.

As long as education continues to happen, it would be okay. Since we don't go to the HTC as often, HSC is our main point of contact, so it makes sense to support the work.

I think that dues are okay, as long as they are low enough that anyone who needs the information that HSC offers can get it. I have fantastic health insurance, but for those where \$50 or \$100 would be a financial hardship, I'd hate to see them not be a part of HSC. \$15 or \$25 should be affordable.

I would want to know more about what the dues are being used for. If we need the money, that's okay. How will the dues be used to benefit the members? I don't mind paying as long as they are going for something good.

***About 54% of people who responded to the survey said that they did not think community awareness of HSC is very high. What ideas do you have for increasing that visibility?***

I agree 100%. I used to be really involved. The magazine was done for the hemophilia society, and I was involved with producing it. It was a great communications piece and a good talking point that you could share with others.

I know we need to go to Web-based, but I don't think we're doing anything much to increase awareness outside of the community.

It seems to me that in 2011, the knowledge about the disease is very low. People don't know there is help for them. It seems like some of the other regional organizations must be doing things we could learn from.

I think that what's been done in the last few months since Emily started has helped to clarify The Society's role. Before that we didn't know what they were doing or what their role was. The lines were so blurred between HTC and HSC. Some clarity is good in terms of spelling out exactly what the society does and is responsible for and where the money goes.

There's good turnout for Education Day and the Christmas party, so that's a great way to build awareness. Members could bring their friends and family to introduce them to The Society and help them get educated about hemophilia.

***Similarly, 27% thought that communication with the community isn't strong and 38% were neutral. Do you have ideas for how to address communication with members?***

I really like the blog and the newsletters. They have been awesome.

I thought I'd signed up for something on the new Web site, but I think maybe I didn't do it or didn't do it right because now I'm not getting the newsletter. Maybe checking in with people to make sure that signing up for the new site is going okay.

It's a small group with people from different backgrounds and geographic areas, so it can be hard to unite us through one form of communication.

There has been a significant improvement in the last year. Even in the last few months.

I'm getting the newsletter. It has good ideas about how to get additional information. In the past, the links weren't set up. That has changed a lot now. Before January, that was not true. Keep it up.

***Only 14% of people think that HSC does a good job engaging volunteers. Do you have thoughts on that?***

Return phone calls, show a genuine interest in people who offer to volunteer.

There hasn't been clear communication about that in the past. I'd like to know specifically how to get involved and what it might take.

We hear how burned out everyone is on the board, but aren't sure how to get engaged. And, that burnout doesn't make it sound very appealing to get involved.

I signed up to volunteer at the holiday party and never heard anything back about it.

I'd be interested in it, but I have never even seen a request for volunteers except for board members.

***Finally, is there anything else you want to share or any ideas you have for the HSC board?***

With the new director coming on, HSC has an opportunity to put it out there, reach out and sort of try to reengage us.

There are a lot more people in the community that would be willing to be involved and help and give recommendations, but during that quiet period of time, it was like a clique. It's time to get out of that group of certain people and invite other participation. They were not welcoming and they need to be welcoming to all of us – even those of us who are not as involved at HTC anymore because their children are older or have access to other services.

We applied to go to Washington Days several times, but just the exclusive group got to go. There is an opportunity to build a strong organization with lots of positive people, like it used to be.

Strategic planning and talking to members is a very positive thing. I'm so glad that the board is investing time in this process and in talking with not just the insiders, but others who have ideas and opinions. It's a great step.

There has been a lot of progress since Emily has come on. She has helped the board be the best it can be.

Education Day will be a good opportunity for people to meet Emily. The blog is great, but nothing beats knowing someone face-to-face.