



Hemophilia Ontario

Looking Back and Moving Forward: A Dialogue with Members

Report on Hemophilia Ontario Focus Group Sessions

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Executive Summary

Over two months in Summer 2017, Hemophilia Ontario completed a series of focus group sessions with its members. These conversations will help set organizational priorities and assist with program planning for 2018 and beyond. A total of 38 individual members were engaged across 11 sessions. The same questions were asked at each focus group, but every session was unique due to the dynamics of the participants involved.

The groups shared their fondest memories of Hemophilia Ontario involvement, including specific programs, a sense of family, and the importance of advocacy. Asked to rate Hemophilia Ontario in recent years on a scale of 1 to 5, the average response was 3.32. The most common response was 4.

There was a lack of consensus around the effectiveness of Hemophilia Ontario communications. Some felt they were very effective and completely satisfying. Others felt there were major, ongoing challenges that are a priority to be addressed. Similarly, there was no consensus about how to proceed with online versus in-person activities. In order to reach out to newly diagnosed families, there were requests to create a new event that provides this group with targeted information and support.

In understanding how to get other people involved, participants identified the need to give back. Many people identified the importance of building and supporting a family environment. When asked what families need most from Hemophilia Ontario, the general consensus was education and peer support. Other suggestions included programming related to pediatric-adult transitions and opportunities for women's bleeding disorder care.

Participants were asked about information they would like to receive from their clinic due to a request for feedback from Reframe Health Labs. Separate and explicit consent to share those responses with the third-party organization was obtained in all cases. Participants had several recommendations, although they also questioned the need for another app and whether or not this could be incorporated into existing technologies.

When asked to identify the number one thing to change within the organization, participants referenced improved communication, transparency at the governance level, more family-friendly events, and support for newly diagnosed families.

Finally, when reflecting on how Hemophilia Ontario had impacted their lives, participants mentioned the sense of community, pride, gratitude, and the desire to make sure the organization is able to provide those same benefits to families in the future.

A. Introduction

As part of a year-long engagement process, Hemophilia Ontario established a Focus Group series to solicit feedback from members and other stakeholders on the organization. The primary aim was to learn how Hemophilia Ontario programs and services can be the most effective moving forward.

In April 2017, all five Hemophilia Ontario staff members participated in a process to identify potential locations and dates across the province. The sessions were to be held over the summer, each attended by the Executive Director and one supporting staff member. The team identified 23 locations and established a calendar that began June 1st, 2017 and ended on July 10th, 2017.

Information and promotional materials about the Focus Group series were developed. The opportunities for involvement were broadcast to the entire Hemophilia Ontario email distribution list multiple times. The dates and materials were also posted on the agency's Facebook and Twitter accounts, along with reminders, and the series was further advertised in *Blood Matters*, the Hemophilia Ontario magazine available both online and in print.

Due to the travel expenses associated with a province-wide series, focus groups required a minimum of four pre-registered participants in order to proceed. In cases where a scheduled date had fewer than four participants one week out, the focus group was cancelled. Those who had expressed interest in participating were encouraged to participate by one-on-one interview over the phone or attend another focus group in their area that would be proceeding.

All focus groups, whether one-on-one or in the group setting, or in-person or by phone, consisted of the same questions:

1. Think back over all the years that you've been involved with Hemophilia Ontario and tell us your fondest memory.
2. Looking back at the last five years of Hemophilia Ontario events and activities, how would you rank the organization on a scale of 1 to 5 where 1 is Poor and 5 is Exceptional? Why did you choose that score?
3. How effective is Hemophilia Ontario communication? Do you feel you get all of the information you need when you need it?
4. If you were inviting a friend to participate in Hemophilia Ontario, what would you say in the invitation?
5. What do you think individuals and families with inherited bleeding disorders need most from Hemophilia Ontario?
6. Aside from personal information about your treatment or upcoming appointments, what information would be helpful in an email update from the clinic? (*Changes to clinic hours, Information about medication availability, new research findings about hemophilia, other?*)
7. How should Hemophilia Ontario balance its online and in-person activities?

8. How should Hemophilia Ontario reach out to newly diagnosed families or individuals who have never been involved before?
9. Suppose that you were in charge and could make one change that would make Hemophilia Ontario better. What would you do?
10. In what ways is your life different because of your participation with Hemophilia Ontario?

Question #6 was provided by Reframe Health Labs as part of an ongoing project with St. Michael's Hospital. Separate and explicit consent was required from participants in order to provide their feedback to Reframe Health Labs. In cases where consent was not provided from all participants at a particular focus group, the question was withdrawn entirely.

After cancelling some sessions due to lack of pre-registration, and scheduling one-on-one interviews with those who expressed interest in participating anyway, a total of 11 focus group sessions were completed between June 3rd, 2017 and July 27th, 2017. 38 individuals participated in the focus groups, not including staff support.

All regions were represented in the focus groups, with the exception of NOR. Five dates and locations were scheduled across Northern Ontario but only one registration was received. The individual who registered did not respond to attempts to schedule a one-on-one interview.

The focus group participants ranged in age from 15 to 65+ and had a breadth of experience with the organization from brand-new members to those who have been involved for many decades. Some participants were directly affected by a bleeding disorder, others were parents of children with bleeding disorders, and others were unaffected long-time volunteers or community stakeholders.

Every focus group was very different, with each group voicing distinct priorities and opinions. To almost every question, there would be one group that answered strongly in a positive way while another group answered the same question with negative impressions. Suggestions for future direction from one group would sometimes directly contradict previous suggestions from another group. This variety in responses indicates the diverse nature of the province, the bleeding disorders community, and the challenges inherent in making organizational change. Despite these differences, however, there were also some very strong themes that emerged and a definite sense of hope for the future.

B. Results by Question

1. Think back over all the years that you've been involved with Hemophilia Ontario and tell us your fondest memory.

The idea behind this question was to find some common ground before taking on more challenging territory. It was also an opportunity for participants to reflect on all of their experiences with Hemophilia Ontario, and not just the things they would like to see changed.

A significant number of responses centred around specific programs, in particular Camp Wanakita, Pinecrest Adventure Camp, and Just The Guys. These experiences went beyond attending as a child, to becoming a volunteer with the program, meeting other parents, and developing leadership skills.

There were also a number of responses about work during the tainted blood tragedy and around HIV/HCV infection. Despite a very emotional and difficult time for those who were involved, the participants who shared it as a positive memory all mentioned the same things:

“So those people, they were the most welcoming. They made you feel like part of a family. Didn’t matter what event took place, they were always very friendly and that always stuck with me. I think that’s what made me join in the first place... just the way they’d talk to you, they’d make you feel how important it is to be part of it.”

There were many references to the camaraderie and importance of strong advocacy related to the issue.

Other participants spoke of being personally engaged:

“Mine is the planting of the trees in Etobicoke. It was just nice to see everybody together, doing something good, and know that one day I could drive by there and know that those were the trees that we planted.”

“Hemophilia Ontario Youth [...] had really fallen apart. So I jumped back in and took charge, and we had some really great staff at the time who were really energetic and really excited to put something together, and so when you have staff who are excited to do new things and you have volunteers and young people who are excited to do new things, things actually get done really well. [...] It’s still spoken about by a lot of us.”

“My favourite memory would be the annual general meeting which I have attended, it’s just great. It’s very informative. I think as a stakeholder for myself, I get to learn a little bit more here about what are the challenges and what are the issues facing the various chapters. [...] So the opportunity for me to come and speak with, or be engaged in any event like this, is very meaningful for me.”

Several responses highlighted social opportunities for members to connect:

“When we have our Christmas parties and Santa comes out and the kids frenzy. Seriously, it’s fantastic. I know that’s simple, but the kids get beside themselves. So to me that almost makes it worth it – the work we do to raise funds and whatnot to have a Christmas party or holiday party. So I guess that would be the annual kids... with big smiles... that’s always great.”

“I would say it’s all the times that you get together with your people who are going through the same thing that you’re going through and getting feedback, and you’re just talking about different things that only we can talk about because we’re all going through the same thing. So all the get-togethers.”

Only one participant reflected having no fond memories at all. In all other responses, the underlying theme was the importance of community and shared experiences.

2. Looking back at the last five years of Hemophilia Ontario events and activities, how would you rank the organization on a scale of 1 to 5 where 1 is Poor and 5 is Exceptional? Why did you choose that score?

This question is an example of where focus group participants had a very broad range of responses. Several participants felt unable or unwilling to give a specific number score, but for those that did, the responses ranged from 1 to 5 and everywhere in between. The average number of all provided scores was 3.32. The most common response was 4.

In explaining why their score was chosen, participants reflected on the strength of existing programs, good communication (although some participants provided a low score and gave poor communication as a reason), and the organization’s willingness to make change.

A selection of representative responses includes:

“Strong leaders are stepping back and it is difficult to develop new leaders. The core of motivated volunteers still exists but they are burning out.”

“Could improve with assistance for employment and identifying compatible careers.”

“I’m trying to make it better for myself. I’m trying to get out of it what I need, basically.”

“Well, I agree with policy – you need policy to do things, but when policy starts running my life or running my organizational community life, we need to step back and ask, ‘What is this for? Why are we doing it this way?’ Because how are we connecting people – we’ve got people all over Southwestern Ontario, all the way up north and around – we don’t know each other at all.”

“Summer camps and family camp are key.”

“This focus group, this is how we improve ourselves. I would say four. Why I like this organization and am proud to be here is because the group is small as far as charitable associations, and we are very, very, very cost-conscious and the, you’ll hear it from all organizations, it’s all for the people or whatever. But you know... There’s so much passion.”

3. How effective is Hemophilia Ontario communication? Do you feel you get all of the information you need when you need it?

Conversations related to the question of communication went in one of three ways: participants either felt the communication was very effective, or they felt it was consistently ineffective, or they focused on the need for increased online communication and through social media.

A recurring theme was the challenge with the Hemophilia Ontario email distribution list. Several participants reported not receiving emails at all. There have been problems identified with the organization's distribution platform and changes are being made, which should be resolved by the end of 2017.

Comments related to the Blood Matters newsletter were also split. Some felt it was still a valuable tool and enjoyed reading it in hard copy. It was referenced as an important tool to connect with aging members who are not connected online. Others felt that it was a disproportionate expense for what they assumed was a small number of people who read it. One participant commented on the timeliness of the information and the disappointment of receiving an issue that advertises events which have already passed.

Some participants also expressed confusion related to the changes in staffing structure at Hemophilia Ontario and not being clear about who to contact. One participant mentioned leaving messages and not always receiving a call back:

"I know that when I call because I'm looking for some information, I don't know who I'm supposed to be speaking to, so I leave a message in the general mailbox and it feels like sometimes I don't get my phone calls returned."

Another participant mentioned the opportunity to improve communication with donors through personal outreach:

"The difference is, I donated a friend – their parents passed away this past year and I donated to [name of charity] which is a group that helps people that are homeless and without work. I got a phone call thanking me for that donation, and it was not big. A personal phone call. And I thought, Hemophilia – we could do that. We used to do that, we used to have phone trees."

One participant described a recent conversation with her son about Hemophilia Ontario, which highlighted the need for fast, accessible information without having time to invest in events and connecting with others:

"And he said 'I want information and I want information and to know where to go. Who do I quickly, you know, if I have a question about pain management, which I'm dealing with right now, where do I go? Who will give me current information, or is it easy to find on the website.'

He said ‘My life is busy right now so I don’t have time for the community connection, even though I value it. But right now, where I’m at, I don’t have time for that, but I really need the information. So how can Hemophilia Ontario find ways to communicate quickly and easily, accessible information on pain management or whatever situations you might encounter?’”

Other comments related to communication highlighted questions of content. One participant noted:

“I get lots of Hemophilia Ontario emails – sometimes too many and they are not always relevant.”

Regardless of whether participants were satisfied or dissatisfied with Hemophilia Ontario communications, it seemed to be agreed that efforts need to be intentional and modernized. Moving forward, the organization needs to ask: Are we telling members what they need to know? Are the communications unique or are they similar to other sources? With limited resources, Hemophilia Ontario needs to focus on priority areas and execute with consistency.

4. If you were inviting a friend to participate in Hemophilia Ontario, what would you say in the invitation?

This question meant to get to the heart of what Hemophilia Ontario is as an organization: what is it about the organization that provides value, why would people want to be involved, how would a member describe its impact to the community and in their own lives.

Many members found their responses difficult to describe in detail, or were unclear about what exactly the question was asking. There were a lot of answers that explained it as “giving back” or “helping others.”

For participants who were able to expand on their replies, a major recurring theme was the importance of advocacy:

“We need people to come and advocate for other people, to help make fundraisers so we can provide education and outings for families to bond with other families that have a similar situation. It’s important, I think. That part’s important.”

“I’d say that the most important thing that Hemophilia Ontario can do is advocate for patients – for people who require blood products. I’d simply say ‘wanna come out and support Hemophilia Ontario, and by doing that you will help ensure that people who need blood products in Ontario will continue to get them, because it’s not a guaranteed thing.’ So we need people advocating, we need strong support, and that would probably be it. I would say this is serious business and we need support.”

Other participants referenced the changes in care:

“I would sell people on the idea that it’s a new day. We’re a lot more in tune with what’s going on. Being a hemophiliac isn’t a death sentence like it used to be.”

But the most common response was the importance of building and supporting a family environment:

“For me, it would be like a family that you can’t get through your own family. Because it’s unique in terms of everyone kind of going through the same thing, but maybe at different phases of life and stuff. So I think that’s the thing that I found when I joined, that I really connected with people in a different way that I never did with my parents or my siblings because they – even though they knew because they were helping – they weren’t directly affected like I was.”

5. What do you think individuals and families with inherited bleeding disorders need most from Hemophilia Ontario?

This was a question where there was almost unanimous opinion across all the focus group participants. The overwhelming response was education and peer support.

Education was highlighted for its importance to members related to developments in treatment, changes in available products, being a trusted information source for new parents, and providing education opportunities across the entire province.

“Programs. Things like Just the Guys, Pinecrest, family summer BBQs, outreach programs where they’re communicating what’s going on with the latest products that are available.”

“People don’t have the knowledge to be able to participate. We should use events like Just The Guys to discuss the Standards of Care and the need for more resources. Use plain language, explain the deficiencies, ask if people are having issues.”

Almost every single session referenced an old Hemophilia Ontario program where families were matched together to provide moral support for the newly diagnosed. The recurring theme was the isolation experienced by community members, the lack of connection available despite Facebook groups and other online resources, and the importance of making personal relationships.

“But if there was peer counselling, [that] would probably be the best. For sure. So that the parents know, from another hemophiliac, because most parents who have young kids who are hemophiliacs have no clue themselves, where does this come from – they don’t know anything about it themselves.”

“They need the support. They need somebody to call when their child is having this problem, when their child is having this problem that nobody else has, and they have

nobody else to talk to. Talking to somebody who has it is a lot better than talking to somebody who doesn't know what the hell is going on."

"Moral support. Moral, physical, financial – especially if you're new to it, it's completely different. Your life has gone from yellow to red in seconds, and now you have to adapt to red instead of yellow that you thought was going to be for the rest of your life. So to have that support system to help you teach, help you learn, help you live, you wanna support your child – that support is huge."

Another recurring answer to this question, related to education, was the need for advocacy and the importance for Hemophilia Ontario to work to make sure clinics have the resources to meet the Standards of Care.

Other specific program suggestions included a renewed focus on supporting the transition between pediatric and adult care:

"<Pediatric Clinic> goes from this warm, loving community, to cold <Adult Clinic>."

"Yeah, there's a nurse there, but you don't really know. Because as a parent, you want to follow that child there to make sure that, 'you're here, you're here.' Instead of just put them on a bus and, 'okay, bye, see you.' I have to tell you, I did that with my son, and I went through so much separation anxiety that I cried for a week."

"And certainly in terms of other information, the website is good but it's very important that there's a continuity of care – that there's a recognition of what's important and what's not, and what to expect and what not. A child who is under the care of a loving parent, all of a sudden they have to navigate into the world of adult. It's pretty scary. All this time they've been under the umbrella of Mom and Dad and now it's like, 'aahh, what do I do?'"

"We need to engage the youth more and bridge the communication. My son is 15 and I think [hematologist] should be communicating more with [my son] and less with me."

And continuing to grow and support the area of women's bleeding disorder care:

"Also, I've been on the Code Rouge website... The thing that threw me off from that is that I didn't see myself in anything on that website. Like younger people... like I couldn't connect with it. I also felt like the vast majority of information on Code Rouge was strictly medical, and I feel like the medical stuff is important and needs to be there but I feel what also needs to be there is the social factor."

"And I think we'll find as things get clearer that there's a lot more women out there with bleeding disorders, that have Von Willebrand or whatever. I think there's a lot of people that have never looked at it that way. And I think again it's this organization that would

support that. And while there's Code Rouge and stuff like that – stuff that in my world seems to go much higher level, it doesn't seem accessible to me.”

6. Aside from personal information about your treatment or upcoming appointments, what information would be helpful in an email update from the clinic? (*Changes to clinic hours, Information about medication availability, new research findings about hemophilia, other?*)

After the promotional materials for the focus group series were distributed, Hemophilia Ontario was contacted by Reframe Health Labs about a project in development with St. Michael's Hospital. They requested an opportunity to participate in the focus groups to receive feedback on a tool that would provide communication between clinics and patients.

Hemophilia Ontario agreed to include one Reframe Health Labs-provided question in the focus groups, with the understanding that it would require separate consent and feedback would only be shared from groups that provided unanimous consent.

During the sessions, there were some questions in the raised about the need for this kind of project by the participants. Some asked why it could not be included in the myCBDR app and many people expressed that they are being overwhelmed by multiple apps or duplicate communication tools.

Suggestions received from the groups included:

- Contact phone numbers and emails for clinic team members;
- Research – both general new advances and opportunities to participate in studies;
- Test results and imaging (or if privacy restrictions will not allow that, then a notification when results are available so patients can call for an update);
- Reports from consults or referred specialists (or, as above, a notification that the reports are available);
- Clinic appointment reminders;
- Communication about transitions between pediatric and adult care;
- Updates on how much factor a patient has left;
- Information about changes in personnel or with the clinic team;
- General best practice in hemophilia reports;
- Special deals or partnerships for clinic patients (e.g. discounts at a local gym);
- Information about what to do if patients have problems in an ER or when travelling;
- Other services offered through the clinic.

A sample of representative responses:

“Anything. You would just like to hear from them! I think they've dropped the bomb on us, and it's been, what, seven months since we've heard from them.”

“My son would like to see new research advances. He would love to hear what’s happening now.”

“I think for patients that are transitioning from a pediatric clinic to an adult clinic, I think if there were more information to help with the transition, that’s helpful. Because you can have a one day thing where everyone transitions, where they see the new team. That’s fine but I think if you can have some kind of a better communication plan or some kind of form put together that would make the incoming patient feel more comfortable, I think that would be helpful.”

“I get everything that I need.”

“When I was treated in [city], I used to get a two page report summarizing my visit, my levels and my results. I don’t know if that can be sent as a PDF, I don’t know if privacy legislation allows for that. I think that’s a great idea.”

“It might be good for them to add what’s happening in research in hemophilia. I never receive anything like that from the clinics.”

“I understand people can get research fatigue, but [name of clinic] will send me a survey every year on the day of my birthday. Sometimes there’s like ‘win a starbucks’ or something. It’s sort of an interesting idea.”

“Any updates, even social updates or whatever they may think, just to keep us in the loop. Maybe something like that would trigger us to say ‘oh I should go, for whatever reason, maybe now is the time I should go. It could be a reminder.”

“I think it depends on the patient. Because new patients are going to want a lot of information. New parents especially are going to want a lot of information about what’s going on, so they can feel safe with their kid’s condition. Obviously it’s not something they expected, that they’re fully prepared for, so any bit of information can help. For someone like me, I have it kind of handled at this point but updates would still be nice. Just monthly updates about what’s going on, who’s doing what.”

“Knowing what research is being done, both generally and opportunities to participate. Information about clotting factor and gene therapy. Anything else of interest, like staffing changes or increases or changes in physiotherapy.”

“CBDR logs use of factor. It should ring an alarm if there is a potential serious injury, which could trigger follow-up email and offer of support from the clinic.”

“The inside look at hemophilia.”

7. How should Hemophilia Ontario balance its online and in-person activities?

This question had a wide range of responses and no consensus from the sessions on the most appropriate way to move forward. That might be expected as an online presence is critical in 2017, and also a cost-effective way of serving such a large geographic area, but face-to-face communication remains essential for the personal connection.

A number of participants reflected on the inequities in existing services based on locations (i.e. that larger or more urban centres have more opportunities for involvement than other areas of the province).

Interestingly enough, the focus groups themselves received more participation in areas where Hemophilia Ontario has not typically offered programming in the past. For example, the Hamilton focus group was cancelled due to lack of registration but there was a very engaged group at the Kitchener-Waterloo session. Similarly, the London focus group was cancelled due to lack of registration, but there were successful sessions held in Windsor, Tecumseh, and Woodstock. A lack of engagement or involvement in smaller areas might only be a reflection of the lack of opportunities that have traditionally been available.

Responses preferring a focus on activities in-person included:

“My preference would be in-person. You know, information is shared easily online but if there’s going to be some interaction it should be personal. One on one or in a group like this.”

“I’m older so I like in-person myself. Especially if something is going to go maybe more than 45 minutes. I find my concentration is not there. It might be like that for a lot of people too. And if it’s not in-person, you’re listening to your phone.”

“I prefer the in-person as well because I like meeting parents and other kids interacting with my son. He’s only 5.5, there’s only a few activities that we can do in the city. Right now we are more on the online communications part. I guess more activities for younger kids.”

“So if you’re going to do in-person, that’s great, but you’ve got to do very hyper-regional events. You’ve got to have the same quality of offerings here as in London, as in Ottawa, as in Sudbury. I’m preaching to the choir; you know this. But it’s tough. It’s a big ask. It’s a big mandate, and it’s not an easy thing to do. So it’s great being here when so many of us are here, but you can’t always pull everyone into Toronto all the time. And you can’t send the Torontonians out all the time, because we just don’t have the funds.

I think about that and ask how can we think about that and really maximize the time where we go ‘we want to be together’ so that it is really valuable. It’s not just an AGM, it’s not just a meeting. For example we’re going to have a weekend and it’s going to be fun for the kids, it’s worth my time to travel for two hours because of what’s going to

happen. That's a lot of work but that can be done. And that will make me feel more connected – it'll make people feel more connected with each other

“Provincially in-person is expensive, but that's where the need is. Online doesn't add any value. You need to get beyond the screen and build relationships.”

Support for an increase in online activities included:

“Of course in-person you have a greater intimacy of talking to the person and meeting face-to-face. But I think the online approach is an evolution of communication. It's the chat line. I know you can do it on Facebook, but whoever is on it they can be on it and they can chat and ask questions. Whether you reside in CHS Ontario or CHS national, it's a forum for anyone to meet anyone, 24/7 and you can mitigate the geographical differences, and you're not playing favourites. And they can do it any time. They can do it in the middle of the night if they're having restless sleep, or if a parent has an issue and they just want to have some sort of support from another parent who's gone through what the parent is going through now. Perhaps they're having some sleepless time, want to be able to contribute something. So if you're talking about online and in-person, in-person would obviously be a celebration event or to gather information. Online you can do everything.”

“Historically it's very difficult to get people up to summer BBQs and winter getaways. I don't think there's enough people, because we're so spread out in Ontario and so big. I've always wondered why. It could be demographics, or just the age of... I know there are more kids now that have been diagnosed. Historically it's been up and down, but I always wondered why there isn't more.”

“I almost think with the in person ones – I don't know whether it's regional or provincial wide but one to two in-person events per year probably seems reasonable. Anything beyond that, I think people are just so caught up with their own lives that that seems hard. People don't feel like they need to because they're comfortable – treatment's good, physio's good, so they're comfortable, they don't need support if they've never had the flavour for it. You gotta have the flavour. So I think one or two in-person events, it would just be purely social but no education because the education stuff you can do online. You can sit at a webinar, and have a doctor talk online. Why do I need to go there and sit and have a doctor talk to me face to face when I could just have a doctor talk to me on the computer while I'm in my pajamas.”

“Online is becoming more important when you consider the cost and logistics of covering all of Ontario. Urban patients benefit more from in-person events than rural ones.”

“Face-to-face is only one shot, but webinars can be shared and revisited.”

“We only come to [clinic location] 2-3 times per year, so electronic is important.”

8. How should Hemophilia Ontario reach out to newly diagnosed families or individuals who have never been involved before?

In answering this question, most sessions went through a larger conversation about changes in hospital policies and privacy legislation. Participants who have been involved for many years referenced how important it was to have Hemophilia Ontario as part of the clinic team that met with patients. Although Hemophilia Ontario still has a presence at all nine Hemophilia Treatment Centres, the opportunity to engage directly with patients as part of their clinic visits has drastically changed. Participants also felt it was important for Hemophilia Ontario to be reaching out directly to newly diagnosed families by phone, which often led to discussions about how clinics are not able to provide that information and the agency typically is unaware when a new diagnosis is made.

As those conversations evolved, in several instances the suggestion was made for a special event specifically for newly diagnosed families. This event might be held once or twice per year and provide an opportunity for the families to come meet Hemophilia Ontario, speak to a hematologist and/or a nurse, and start to build connections within the bleeding disorders community.

Other suggestions included revising and updating promotional materials that clinics can distribute to patients upon diagnosis, so that families know what resources are available to them. There were conversations about the ‘new family packages’ that had toys and information and the level of effectiveness they had. Some parents reflected being totally overwhelmed at diagnosis and that most of the materials they were given were not actually valuable. Other participants felt strongly that a brochure was insufficient and that personal contact needed to be made.

The variety of responses included:

“Through the doctors. They should be reaching out to you guys. They should probably give the website or your numbers to all their patients, to connect with you for sure.”

“I think there should be some kind of seminar, I guess, for lack of a better term. [...] So I think that, you know, a panel discussion or something where the person, the parents, can get information from all different sources in person and then they can ask questions and do what-not and then request any written or printed information.”

“I would want somebody to come to the bedside and explain everything to be verbally, not just hand me a pamphlet – here you go – with a 1-800 number. I would want personal, verbal resources and things like that.”

“A more passive approach would be better. Encourage them to stop by events slowly and build to become actively involved. Get past heavy recruitment: we aren’t just here to ask for money. People are busy and get asked by multiple charities for support.”

“Become stronger electronically, be prominent with SEO [search engine optimization]. We need to be more than the website, like a knowledge portal or library.”

“There used to be a lot of support groups for newly diagnosed parents. Someone like my mother, who raised a son who was healthy, or someone like me, or some of my friends who are equally in great shape. And those groups have fallen by the wayside, because of things like lawyers and privacy concerns, and it’s an absolute crying shame because that’s one of the best resources that we can provide to people.”

“We have no family history whatsoever, so the first source of information is really from the hospital. So I guess the first line would really be the hospital, letting us know about this community of bleeding disorders. I would also prefer if they would have some kind of seminar for extended families. For ourselves, my in-laws and my parents are back-up for while we’re away or while we’re at work, so they are informed but it’s second hand information coming from me. We were hoping someone would sit down with them, or like a seminar for other caregivers about hemophilia so that they have more information about it.”

9. Suppose that you were in charge and could make one change that would make Hemophilia Ontario better. What would you do?

In line with what had already been discussed during the previous questions, there were repeated calls for improved communication, transparency at the governance level [see Section C3], more family-friendly events, and support for newly diagnosed families.

“A new parent’s initiative would have been very helpful. We’re new parents, and then we’re dealing with a bleeding disorder – no family history, we’d never heard of that – and now at this stage with my son I guess – when my son started in junior kindergarten it was very important to me for the teachers to be aware of his bleeding disorder. Because teachers are trained to do first aid with kids with allergic reactions, but they don’t even know what hemophilia is. So I had to put together a PowerPoint presentation and show them what it is.”

“Better to have fewer, larger events, than multiple events that are not well-attended due to the location or choice of activity.”

“Provide more opportunities for involvement, members aren’t informed enough about what is going on. The General Meeting is very bureaucratic.”

“I learned that my son was eligible for a Make-a-Wish trip due to his hemophilia through another member. Those are the types of benefits and information we should be sharing.”

Multiple participants mentioned the need to reconsider the name of the organization as the #1 change that needed to be made. With such an increase in the awareness of Von Willebrand Disease and other platelet deficiencies or bleeding disorders, several people mentioned not initially recognizing that Hemophilia Ontario or the Canadian Hemophilia Society were their associated patient advocacy group.

“Brand recognition [...] There’s other bleeding disorders that are out there.”

“I wonder if it would be useful to change the name of the organization. Like I don’t have hemophilia – it’s a broad range of diseases and also experiences. So I wonder if that would get people more involved and increase the membership. I also think it makes it confusing for people. I saw the pamphlets [...] I was confused about it. I was like, ‘Is that for me, or is that not for me?’ And I ended up just asking someone, ‘Is it worth me calling this place?’”

Other topics that were raised include volunteer recognition, better use of existing skill sets, and increased fundraising:

“I’m going to go with volunteer recognition because that’s one of my disappointments at how it’s done, and the way it’s done. Back in the day they used to have a volunteer dinner once a year for everybody and they’d thank people for their support and stuff like that, which was better than nothing. I don’t know how they do it now but I don’t like it.”

“Have the right people in the right positions – staff and volunteers. Match positions and skill sets. Don’t want to turn people away, need to tell people what the expectations or opportunities are.”

“If we had more revenue, more event sponsorship, we could serve more people”

“What are we here for, we want to think ‘treatment for all’. That’s what this is about, that kind of thing. So if we keep the mission, the vision in front of us that will help spur us on into whatever needs to be done. That’s what this is all about.”

10. In what ways is your life different because of your participation with Hemophilia Ontario?

As the focus group sessions wrapped up, despite what had been at times very difficult conversations, the participants unanimously described positive influences in their life thanks to Hemophilia Ontario. Although some mentioned the stress or workload involved with volunteering, everyone who participated reflected on a sense of community, pride, gratitude, and the desire to make sure the organization is able to provide those same benefits to families in the future.

A representative sample of responses includes:

“It has had a direct impact on my health. I would have kept bleeding and I learned who to talk to. We have done a lot to improve the quality of care: Standards of Care, recombinant products, compensation.”

“I wouldn’t be as educated on the topic. I wouldn’t have met other people that I can bounce ideas off about it or like [...] I wouldn’t know anybody else, so I guess opening up communication about my condition. I’m kind of on the opposite side because I like to educate people. At first I was like “absorb, absorb absorb” but now I like to support other people who are scared, who’re not sure what they’re going through.”

“I know others are out there. I am not alone.”

“I think it’s made our life much more manageable, having that. I really think when you’re educated and you have that connection, it makes living with it much easier and you can also help your son too. Because when we’re getting educated, he’s getting educated. And I think that’s... been able to manage it through all the different stages of life too.”

“Hemophilia Ontario, together with the clinic, what it used to be, as you can tell we used it as a tool as a family together. And just to hear their answers – it’s very emotional. Just the pride that I feel especially with my two kids and everything they do, it’s just really important that we keep Hemophilia Ontario strong. It has made me a stronger mother and a stronger wife when I had to be, and a big advocate for anyone with bleeding disorders. It made me stronger, more educated. And I don’t want to stop that.”

“In the big world of hemophilia, you actually feel like it’s a small world and you belong to something and you’re not standing out in the cold by yourself.”

C. Results by Theme

As part of the focus group conversations, multiple themes were identified across participant responses in almost every session. Because these themes would be carried across several questions, this report addresses them separately from the Results by Question section above.

Although every focus group was asked the same questions, the direction of the conversation was indicated by the priorities of the participants in attendance. As a result, topics were raised in some sessions that did not come up in others. To ensure this report reflects the wide-spread opinions of all participants and not only the priorities of one or two individuals, the themes being addressed in this section only reflect ideas that were raised in a minimum of five different sessions.

It is important to acknowledge the contribution of the focus group participants in this area. As a patient advocacy group, Hemophilia Ontario should reflect the needs and concerns of the patients it represents.

1. Emotional Support

The importance of providing support to members was a theme carried across almost every question, at almost every session. Focus group participants spoke about the fear and isolation of living with a bleeding disorder, and the integral importance of Hemophilia Ontario to provide support to individuals and families through these times.

Specific requests were made for increased access to mental health services, the importance of encouraging patients to make use of their clinic social worker (or to ensure every clinic has access to a social worker), and the need to connect with other members of the community with similar experiences:

“Like I remember when I gave birth to my child and I was told that he was a hemophiliac, I remember I just cried. I had no idea what that was, I knew I had hemophilia in my family but I didn’t know what that meant until the day my kid was born and I felt like I was alone and I’m the only person with this and I don’t have somebody to go and talk to, right?”

“And people don’t understand. You’re not in the same boat, you don’t understand. As much as you try, you don’t understand. Some people, some of my friends – I didn’t even tell my friends. For years. So you can’t talk to them about it either, because they don’t get it. Because you’re healthy looking – they look at your body. It’s not your body. You know, my body looks great but it’s not my body, my brain’s a mess.”

“It’s hard. You always feel like you’re second class. You’re not ‘one of them’ – the healthy guys. At least that’s what I felt. Especially when I was in high school and everybody was aware, and you weren’t allowed to do certain things. That pissed me off a lot.”

As outlined previously in Section B, there were repeated requests to bring back the family matching program or other types of peer support. Some participants questioned the need for gender-specific support in 2017:

“Gendered programming is ridiculous. I avoid the programs because they make no sense to me. Why do women get wellness and men get camping? It seems so old fashioned to me.”

2. Wider Lens for Education

Hemophilia Ontario and CHS have many education opportunities available for members about their care and the focus group sessions stressed that should continue. The recurring theme for education, however, revolved around the need for broader education than is currently available.

Conversations repeatedly returned to the lack of education and awareness within the general population, and even within the medical community:

“The support is there for our members. But the education for the general public is not there.”

Participant 1: “Or the fundraising for the general public is not there.”

Participant 2: “Yeah, we focus within our group.”

Participant 1: “Every other organization focuses on the rest of the city.”

Participant 2: “You look at any other disease, whatever, cancer... I go talk to them and they say “hemophilia, what is that?” [...] My wife went to go see her GP to find out if she is a carrier – “What is that?” – some GPs don’t even know what hemophilia is.”

“Even my General Practitioner said ‘you don’t need to go to <bleeding disorder clinic>, you’ve gotten through life fine’. [...] But I want to do this for my daughter because I think it’s important”

“When you get a doctor who doesn’t know how to spell it, let alone what it is, that’s concerning.”

“A lot of people really don’t know about hemophilia. Actually to tell you the truth, I didn’t even know until last April that April was Hemophilia Awareness Month. I think that’s really important for everybody to know, and I didn’t really know.”

“But I don’t think that Hemophilia Ontario is in touch with the medical community, because I know of two family doctors that had no idea about hemophilia [...] and it’s because it’s a chapter in a book in medical school, and unless they have a patient, that’s when they have to get up to speed on how to handle it. My daughter, we have no hemophilia in our family, she went to the same family doctor as my son and I can’t remember what her issue was but the doctor who was a very competent person started talking about doing testing to her because she knew the connection to hemophilia, but didn’t realize that it was the wrong side, that she couldn’t possibly have it. She might have something else but it wasn’t hemophilia. So there’s that lack of knowledge there. So I think that should be the role of the hemophilia community is to educate the people who have the most contact. I’m sure there are gynecologists who have no idea that women have Von Willebrand. Why isn’t Hemophilia Ontario or CHS, and I know that’s out of your realm, getting in those doors?”

Other discussions about expansion in education revolved around the difficulty with health care funding in Ontario and the need to make sure members are aware that their care may be at-risk. Participants voiced that many patients take their access to factor and multidisciplinary teams for granted. Those who have not previously been involved in the advocacy required to secure the level of service available now do not recognize that most clinics no longer meet the Standards of Care. Although advocacy with all

levels of government was a priority for many, the majority of the conversations focused around the need to educate the community first about the issue:

“If you look at Hemophilia Ontario and CHS, what is the role it’s going to have? Because, see, part of it is a lot of people are growing up and they have no idea what <participant> and I went through, for example. They’ve never had bleeds, they’ve never had pain. I mean, I’ve had four hip replacements. So I’ve had a lot of stuff happen. A lot of pain, a lot of everything. But a lot of young kids are growing up, they don’t even know what it means. [...] We have to realize that, what can we do, that we’re evolving. That we still have to have the advocacy; we still have to make sure that we have access to care.”

“Kids with prophylaxis are in good shape. We are doing such a good job of taking care of ourselves, Emergency Departments are not confident in providing care, and the province questions if we really need the money for clinic support. It is important for people to realize their care funding is at-risk.”

3. Governance and Need for Change

Many sessions included conversations about governance issues: at the regional level, with Hemophilia Ontario provincially, and with CHS nationally. All of these conversations featured the same themes: a desire for increased transparency and a need for greater accountability to the membership.

Some participants highlighted difficulties in the past as a reason for decline in current participation levels:

“There used to be battles on the Board!”

“There was a lot of stress in those days and we scared a lot of people away. Lot of members, lot of youth.”

The focus group sessions made clear that a significant percentage of members do not understand the relationship between Hemophilia Ontario and the national organization. They were often referred to as two completely unrelated organizations, rather than Hemophilia Ontario being the provincial chapter of Canadian Hemophilia Society. In cases where participants did recognize this relationship, it was repeatedly suggested that Hemophilia Ontario should be separate or seek greater independence in order to improve communication, accountability, and transparency:

“I am worried about the deterioration of our CHS relationship ... People are no longer CHS members ... Opposing views are necessary to move organizations forward.”

“National needs to be willing to allow provincial differences to exist.”

“Hemophilia Ontario needs to maintain independence as much as possible. It will make the whole organization stronger.”

“We need to separate from CHS.”

When these conversations arose as part of the focus group discussion, they inevitably included concerns about the issue of paid plasma donations:

“With CHS endorsement of paid plasma, we will not be able to advocate for compensation in the event of future tragedies.”

“How can the patient advocacy group endorse a policy and accept the risks without [member] endorsement?”

“If we accept the risk of cheaper, plasma-based treatment options, why should the government pay for recombinant?”

Another repeated theme was the need for greater visibility by Board members within the community. Participants shared concerns about knowing who their representatives are, wondering how they can be represented by someone they have never met and who does not attend events.

“Three hours a month, proofreading and hearing political mumbo jumbo about what the organization was going to become, and nothing about the people we were supposed to be supporting. Members didn’t come out to events that we had planned and were extremely successful in fundraising. They’d make cameo appearances or they didn’t have time to be there. There were always three members of the Board that were at every event and it was the same three people every time. The Chair didn’t go, the Ontario rep didn’t appear. It was just really disheartening.”

“The Board needs to remember it is here to support the members. They need to vote based on input from the membership.”

Participant: “Do we have any representative members at the Ontario board, or national?”

Facilitator: “The [region] representative at the provincial board is [name].”

Participant: “Who’s that?”

As a result of this disconnect between membership and leadership, there is a growing lack of trust related to changes that are being made. Participants expressed a desire to be informed about the processes for change and have opportunities to be involved, at both the provincial and national levels. Changes have been made, both by CHS and Hemophilia Ontario, which members feel were not well-communicated or explained. As these changes have the potential to directly impact participants’ lives, the perceived lack of accountability impacts their ability to trust and engage with the organization moving forward.

“I would like to see access to minutes for Board meetings, for decision making. They’re representing us and we have no window into it.”

“Just because there doesn’t seem to be any concern expressed about it. You just wonder what’s the plan, what’s going on that we don’t know about. And that’s what I feel – there’s something going on, there’s something being planned that we don’t know about.”

“We’re out of the loop and no one really cares whether we’re in the loop or not. And it even seemed to me that there’s no – was there a change in the amendments to the constitution for the Canadian Hemophilia Society about how the voting went or the lack of voting? That only the representatives can vote now? And nobody knows, we were never involved, never asked to vote on that.¹”

Participant 1: “So the transitional part was poor, and the communication of how that happened was extremely poor.”

Participant 2: “Which I think made things worse when it didn’t have to be.”

Participant 3: “I lost trust in a few people after that period, which is unfortunate. The way they chose to do it, I guess.”

“There is a real need for improvement in communication. And that’s not just provincial level, that’s the CHS level too, the national level.”

Clearly not everyone will agree with these identified concerns, but as the CHS Strategic Plan clearly states, “Perception is reality. Communications must improve.” These challenges are real and cannot be dismissed as the views of a small minority. If these trends continue, the organization is at risk of losing its inherent value to create a strong community and garner the support required to assist those who are most in-need.

“I think my sense is there’s been a disconnect but the disconnect I’ve experienced – because my son is older and he’s living in Toronto – but the disconnect is that I feel like we’ve lost a sense of community.”

“I’m here to beg for help. That’s all I’m here for... I need a voice. And I need the Hemophilia Society’s voice behind me. That’s what I’m here for.”

D. Conclusion

The substantial time and energy that was committed to these sessions must be acknowledged. Hemophilia Ontario would like to thank all of the participants for their involvement and intends to use the feedback received to direct future priorities and programming.

¹ The Canadian Hemophilia Society by-law amendments were passed unanimously at the 2014 Annual General Meeting. All legal requirements regarding advance notice were followed.

At the end of each focus group, the participants were asked which key issues needed to be stressed as the final take-away. The responses highlighted a number of points that have been addressed in this report:

- The need to grow our membership base;
- The importance of collaborating with the clinics;
- Establishing a special semi-annual event to reach out to newly diagnosed families;
- Re-establishing mentoring or family matching programs;
- Ensuring a big voice for Hemophilia Ontario at the CHS table;
- Becoming more results focused and able to articulate what we have achieved; and
- The importance of sharing stories from the membership.

As Hemophilia Ontario moves forward with its engagement process and program planning for 2018, these key take-aways will inform the organizational priorities. The program suggestions will be thoroughly investigated and implemented wherever possible. Hemophilia Ontario will pursue a culture of transparency and accountability to our members, in alignment with the established organizational values, and be a leader by example for others.

Member engagement is not a one-and-done activity. Hemophilia Ontario is committed to continuing dialogue with the bleeding disorders community to make sure the organization remains at the forefront of developing issues and concerns, and is able to provide the services people want to receive. It is important for a patient advocacy organization to reflect the needs of its members, and the only way to do so effectively is through ongoing consultation.

Anyone who was not able to participate in the focus group sessions but would like to have their feedback included in future priority-setting or program development is encouraged to contact Jenna Foley, Executive Director of Hemophilia Ontario, at any time by phone (888-838-8846 x 17) or email (jfoley@hemophilia.on.ca).