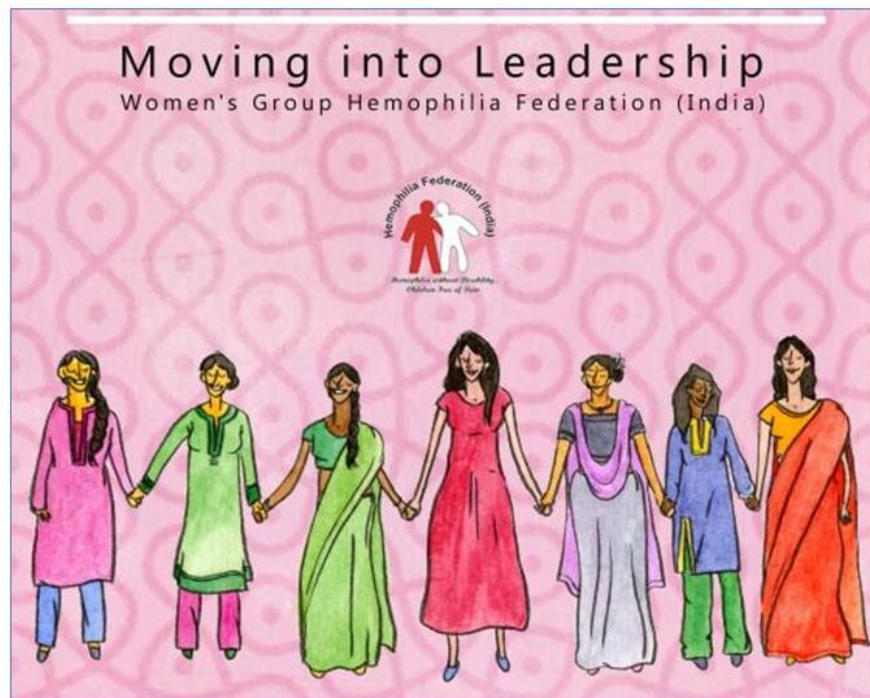


Women's Leadership Guide

Hemophilia Federation (India)



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1. Overview—Why Do We Need Women Group in HFI?

Taking care of someone with a bleeding disorder, (also called PwH—Person with Hemophilia) takes special knowledge, skills and strength. Girls and women who may also have bleeding disorders often belong to a family with others who have bleeding disorders. This program recognizes that to be able to successfully care for someone else, the caregiver must first take care of herself. As a result, this program includes information to help a caregiver who may also be a woman with a bleeding disorder or who may have a daughter or a son who has a bleeding disorder.

Working Together – Men, Women and Youth of HFI

The Women’s Group of Hemophilia Federation of India believe that Working Together with the men and the youth of our Indian community are critical aspects of our women’s leadership programs. It was the men of HFI organization that wrote a grant and lobbied to begin this group. It was the men who provided the energy and resources (by calling upon the youth group) to ensure our training programme was a success. Using a Train-the-Trainer approach 12 women were trained and then they began training nearly 100 other women.

The Women’s Group has strong representation on the Hemophilia Executive Committee through our Chairwoman. We strongly believe that with men, women and youth Working Together through mutual support, we will learn more and grow stronger as a community.

Role and Importance of Women Care Givers

A woman related to a hemophiliac; as a mother or a sister or a partner, plays a very important role in his/her life—emotionally, mentally and physically.

Girls and women with bleeding disorders and carriers, have suffered in terms of treatment and management, economic burden, social stigma, marriage, marital life, emotional, mental and physical torture by in-laws and even sometimes by their partners.

Since the inception of the Hemophilia Federation of India (HF), women have been involved with haemophilia management and developmental activities at both the chapter and national levels, yet there was no proper platform to address their issues in an organized way. Therefore, to bring them under one umbrella, HFI started taking various initiatives from 2011-12.

Objectives

- To Provide Training on Leadership and Capacity Building for making them enable to represent the women in EC of HFI
- To Create a Leadership Manual For Women Group of HFI
- To provide them a platform for exchange of knowledge and women empowerment
- To Create a National Level Women's Support Group and to foster global “Sisterhood” amongst the women care givers

Mission Statement

- a) Empowerment of Women in all respect
- b) Forming Women Support Group
- c) Dissemination of information and knowledge to other caregivers
- d) Identification of more and more women leaders.

Goals

1. To Form Women 's Support Group

How

- A chapter network
- Communication with women group
- Psychosocial Session
- Medical Sessions

2. To educate Women in the bleeding Disorder Community to be leaders

How

- Out Reach to Chapters
- Regular camps for Women group
- Meeting with women group at chapter level

Training Curriculum

- Communication: (To and fro communication, Reporting, Documentation, maintenance of NHR)
- Programme Management: (Planning of Activities, Project Implementation and Financial Management)
- Resource Mobilization: Fund Raising, Advocacy, Lobbying and Income Generation
- Medical Education: (Education and Awareness of Hemophilia as well as treatment and management of the disease)
- Psycho-social Intervention

Creation of this Women's Leadership Guide is one of the deliverables of this project.



2. Leadership Traits and Characteristics

What is Leadership? Why is Leadership Needed in the Hemophilia Community?

"Be the change that you wish to see in the world."

— Mahatma Gandhi (1869-1948)

Leadership is the ability of a person to make sound decisions and to inspire others to perform well. Effective leaders are able to set and achieve challenging goals, to take swift and decisive action even in difficult situations, to outperform their

competition, to take calculated risks and to persevere in the face of failure. Strong communication skills, self-confidence, the ability to manage others and a willingness to embrace change also characterize good leaders.

Leadership is a very essential quality to conduct something or to implement something in each and every field, and therefore, leadership is needed in Hemophilia Community.

No longer do women write books depicting their insecurities and injustices. Now women are writers of Pulitzer Prize winning works and teach aspiring male authors how to be the best they can be. The Indian society is now proud of outstanding women achievers like Kalpana Chawla, Sania Mirza, Barkha Dutt, Shabana Azmi, Deepa Mallik and many more. In a society where it was once unheard of for women to even be educated, women take up the majority of grade school teachers, and many more have blossomed into college professors with Ph D's and MD's.

As women kept making these advancements to individualism, people have taken notice, and now women are considered better contenders for many jobs, men no longer have the full control they once fabricated. With the achievement of all this, women now have so many opportunities that were once a dream, the tunnel they once envisioned so dark and impossible seems like a stairway to light, to the open society of acceptance and opportunity.

The future of women in India looks bright and secure and their role even more important than only being a wife, mother, or daughter. Indian society is changing in terms of acceptance of the many roles of women as professionals, as bread-earners in families and as independent thinking individuals. The traditional Indian woman has evolved to prove herself equal in many professions as well as proved better suited than men in others. The situation for the changing role of women is improving fast.

Example: One example of leadership for the Women's Group would be shown at the Chapter level. In order to conduct a meeting of the Women's Group, one person has to take the leadership first of all to decide the venue, to distribute the

responsibilities among other women, to conduct a meeting, and to look after the things in order to have a successful meeting with follow on actions. This quality of leadership will help to develop the Women's Group in better way.

What makes a good leader?

- Leaders need to have the ability to communicate and motivate people to work towards the vision.
- It is important that they can inspire others to trust and support them.
- The most important trait of a leader is authenticity and self-knowledge.
- A leader needs to know her/his values and belief system.
- This self-knowledge is a compass for navigating complex situations.
- In order to lead, one should have clarity of vision and the ability to communicate it.
- Another important trait is curiosity. Curiosity means more knowledge about new and different things.

Reference: An interview of Diana L. Nelson, Chairman of Carlson Hotels Worldwide, Inc. and Carlson Companies, Inc.

Successful women often credit luck for changing their lives, but there's so much more to the making of a woman leader than luck. Luck is less about good things randomly happening to people who happened to be in the right place at the right time, than it is about perseverance, dedication, and the ability to show up at 100 wrong places before you get that "lucky" break.

Perseverance

As a leader, you are going to come across challenges, and sometimes things won't go according to plan. Women leaders need persistence, perseverance and the ability to not take NO for an answer."

Nurturing Spirit

In the past women have been condemned for being "soft" or being "nurturers".

Consider this—being a nurturer, having a sense of being fair and just, and use of our women's intuition to be are some of our strongest traits.

Confidence

One of the defining characteristics of leadership is confidence in having an "unconditional belief in your own abilities." Having confidence isn't about bragging or being a show off, but about not undermining your abilities and creating a culture that values your input.

Giving Back

It's important for female leaders to look for ways to give back to their community.

Education

India has been a male dominant country where women were treated poorly and taken for granted. With changing times, things are looking better. Still, many women are deprived of

education. It is very necessary for a woman to get education as there is a saying that "if a woman is well educated then her family also gets good values, morals and ethics, as she is the educator of the family."

Education is a must for women, and in our haemophilia community women should also get acquainted with the medical education as she is often the prime caregiver to the people with hemophilia and other bleeding disorders.

Balance and Understanding of Your Own Needs

One of the things a good leader understands is how important it is to achieve balance in her life and take care of herself. Women in general have a belief that self-care is selfish! Consider this —It is like breathing and is vital to our survival.

Vision

A good leader needs to not only be an expert in their industry, but to see the bigger picture, and understand their role in the wider world. They need to believe that change is possible and worthwhile, and be able to convey that message to others in a way that has meaning. This quality is best summed up by one word—Vision.

A leader with vision is a leader who can see the path ahead and inspire others to help them turn a dream into a reality. The qualities that make a good leader don't vary between men and women. After all, it's the person, not the gender that determines a leader. And although women are only just catching up to men in terms of leadership roles, their unique experiences and supportive natures make them more than capable of leading the future.



3. Roles and Responsibilities

It is very important for a Group or NGO that its members understand the various roles and responsibilities so that they can fully participate in events or projects of the group. It is the duty of a leader to clarify the roles and responsibility of members. Once that is done, members can be break into sub teams with the leader of that sub team and the sub team members will see to it that roles and responsibilities given to will be performed efficiently by all the members.

The key points for a Women's Group leader are to:

- Define the broad objective to be met by the group
- Identify and organize women belonging to Hemophilia families in their region
- Conduct regular meetings for knowledge sharing and information dissemination
- Liaise with local Hemophilia chapter on latest developments, updates and communicate them to the women's group
- Provide training in basic care and rehabilitation
- Represent women's group concerns to Local and National level in awareness events

EXAMPLE: One example of an activity that most women's group members will want to participate in will be awareness events. There are many tasks to be performed to host an event and those who participate will need to understand their role and responsibilities.

The Roles we use in identifying, sharing, voting, approving, funding and reporting activities for WGHFI are:

- **Chapter Members:** Women who belong to HFI Chapters throughout India and who wish to participate in our activities. They talk with their Regional Coordinators to identify ideas for new projects and provide the helping hands for activities. They identify issues and offer ideas for solutions.
- **Regional Coordinators:** Women who are leaders for their Regions. They listen to Chapter Members and identify key projects and activities for the Chapters within their region. They encourage new women members to participate in training and meetings. They participate in the Women's Group Regional Council to vote, approve and make decisions in support of national interests for women. They are responsible to have reporting of activities for their Regional activities complete in a timely manner to the to the National HFI organization. They train other women to perform various tasks and teach them leadership responsibilities.

- **Regional Coordinator Assistants:** Women who support and are the backup for their Regional Coordinator, in all aspects. They provide project management support, facilitation of activities and coordination of events for the Women's Group in their Region. They support or perform reporting of activities happening in their Region and provide these reports to their Regional Coordinator for review and approval.
- **WG Regional Council:** This Council consists of the four regional Coordinators and the Women's Group Chairperson. Together, they make decisions in support of national interests for women regarding both ongoing activities and projects. They make sure these activities are carried out under the guidelines of the HFI Constitution.
- **Women's Group Chairperson:** The Leader for the Women's Group who is responsible to make decisions, manage budgets and provides oversight to ensure the stability of the group and that the mission of the Women's Group is carried out under the guidelines of the HFI Constitution. She is also a member of the Executive Committee of HFI.
- **Executive Committee of HFI:** The overall governing body of the Hemophilia Federation of India. These individuals are responsible to make decisions, manage budgets and provide oversight to ensure the stability of the organization and that the mission is carried out under the guidelines of the HFI Constitution.



4. Women in Our Community

There are many relationships that form within our community. Here are some descriptions:

Blood Sisters

Women who choose to help other women. Women who look beyond themselves to form a bond and offer support to other women who play a role in our community.

Carriers—With Symptoms or Without

Women who carry the gene for hemophilia (or other bleeding disorders).

Some women will have bleeding symptoms and others will not. Those with symptoms are considered to have mild haemophilia and should be formally diagnosed so they may be offered a treatment plan and treatment if it is available.

Women Bleeders

Sometimes referred to as “thin blood sisters.” Girls and women can bleed in the same way as boys and men, and a few other ways as well. In early days it was thought that only boys had haemophilia or bleeding disorders. According to the World Federation of Haemophilia “an estimated 1 in 1,000 persons has a bleeding disorder, close to seven million men, women and children around the world, but 75 percent of them don’t know it and receive little or no treatment.”

Girls and Women Family Members

Any family having bleeding disorders may have girls and women that are not affected by bleeding. They should be tested to make sure they are not really a mild bleeder (and at some later date suffer a disastrous bleed). If they are given proper training, they are most helpful to offer support to family members with bleeding disorders and can be very helpful in carrying family burdens if they are kept close to family members. They should also understand their genetic history so as to know if there is the likelihood they may pass this onto their children.

Girlfriends and Wives

A girlfriend or wife of a person with haemophilia can offer positive support through companionship and encouragement. She should take time to learn technical information about the disorder and offer encouragement in physical therapy, regular exercise, healthy living and emotional resilience. She should also provide administrative support through offering to fill in paperwork for medical insurance or job opportunities as this is often something women do better than men. In addition, bleeds can happen spontaneously and if she is helping to run the household and understands how things work, things can run more smoothly.

Inspirational Leader

Each woman in our community must play a role as an inspirational leader. She will find what is in her heart to share with others and search for new ideas every day. By taking on the role of an inspirational leader she will ensure a better quality of life for those around her and for her, as well.

Psycho-Social Support

One of the key roles for the Women's Group is to provide psycho-social support for the women in the community. This is a key role for HFI to build the women's community through a strong group of empowered and strong, women who understand the challenges and can meet them independently or collectively.

Blood Sisters—Women Who Choose to Help Men

Women who are also bleeders or are in some way a part of the bleeding disorder community and have men who have bleeding disorders as friends. There are special bonds they share as if they are their sisters and are in the same family with the boys and men.

Our Role as Friends in Helping Men

Women are known to have special traits. This includes being very organized, intuitive, gentle, and humorous. Some men feel that having women friends bring out the best in them because they don't compete with them as they do with their male friends. Finding the right chemistry between a woman and a male friend can create a very special bond to help the man feel more confident without feeling dependent. There are times a person with a bleeding disorder needs someone to just be there with him for conversation or to put on shoes. It doesn't have to be complicated or difficult to be a friend. It just takes time and willingness.

Our Role as Leaders in Teaching Men About Women

Women Leaders can help set boundaries by being honest about what is in their heart and what they are capable of doing, or not doing. Guidelines can be helpful to establish for situations such as women's camps, women's events, and women's roles. This women's group was founded by men who wished to create a platform for women to be more empowered within their family and in their communities. By showing thanks for this gift, women will step forward to try new things such as training activities, support activities or learning about and trying income earning opportunities.

Making Good Choices With Men

Men and women have gotten along—and not gotten along—since the beginning of time. If a woman sets boundaries between herself and men, she is likely to be more successful than if she just waits for something to happen (or not to happen). She has power that she hasn't yet tested if she has never stood up for herself with the men in her life.

Inspirational and Motivational Ways of Women

Women are naturally gifted with the ability to nurture and encourage other people. They do this with the thoughts that come from their hearts. It is possible that over time and with too much wear and tear on the heart, that these gifts become difficult to bring forward and

nurturing or encouraging other people becomes impossible. The woman who recognizes this in herself, or in another woman, needs to take time to replenish herself and bring back these gifts so that she can help her community. She can do this by many ways including taking classes, talking with other women, reading books or seeing online information.



5. Making the Right Priorities

In general terms, making the right priorities means having a sense of importance and urgency.

Everyone has priorities on a daily and weekly basis, and these priorities may change with time. In the same way, groups or NGOs also have priorities as per their setup or as per the needs of the members, or as per the constitution of the NGO.

It is the duty of the core team of the NGO that they should make the right priorities for the group. A new group (like the Women's Group HFI) has different priorities in the beginning and with the

passage of time, or as the group gets bigger or it fulfills member's basic requirements (like training, etc.) its priorities are different.

In the case of Women's Group HFI also, while making priorities, a few points are to be kept in mind:

- Aligning potential actions to overall goal of the role and women group,
- Allocating resources optimally and choosing activities that provide maximum impact and benefit for members concerned and,
- Ensuring that actions are consistent with HFI and local chapter goals, values and mission.

Example: In the initial stage, the priority of our group is to locate the members and bring them into our group. After some time, when the group starts working on a project etc. we will set priorities accordingly.

Women's Group HFI Meeting Etiquette

1. Your timeliness is important
 - a. Come to meetings on time
 - b. Let the meeting chair know if you have a reason to not be on time
 - c. Return to breaks on time
2. Be courteous to speakers
 - a. No side conversations with your neighbor during presentations
 - b. Ask presenter if they would like questions or comments during their presentation or if they would like them held to the end.
3. Learn about other points of view
 - a. Sit with others that you don't know, if you can in our meetings.
 - b. Try not to jump to conclusions too early and listen instead.
4. Support the meeting leader

- a. Ask how you can help support the agenda and intent of the meeting before the meeting. Should you bring something? Did you have homework to do before coming?
- 5. There are no irrelevant questions, only unanswered ones.
 - a. Be brave; ask if you have questions to understand and clarify what is said.
 - b. Never laugh at someone else's question. You might learn something.
- 6. Turn off cell phones and put other distractions away
 - a. It's ok to take notes



6. Team Building and Delegation

What is a Team?

A team is a group of people who work for and share in the responsibilities of a common goal.

Creating a Team

A leader must select those members who are competent, reliable, motivated, hardworking, intelligent, and who can also work well with others. And, sometimes team members belong to a team because they volunteer. So, whether someone was chosen or volunteered, a good leader is one who appreciates that team members have a variety of knowledge and skills and finds a way to build a good team.

Building Trust

A leader must work to build team trust. This trust promotes team member's commitment to the common goal. It also helps the team to resolve disagreements. The most effective team leaders build their relationships through trust and loyalty, rather than fear or the power of their positions.

Secrets to Success

We need to keep these things in mind as we manage our teams.

- Delegation: Giving continuous opportunities to women at regional level so that they can come up with ideas, which on a broader and gradual scale, will help us in making the network strong.
- Inclusion: Including more women in execution of rules and laws as far as our chapters and regional level societies are involved. Women should be allowed to get involved in the decision making process regarding their chapter and society.
- Education: Giving women awareness in each aspect so that they can be well aware of what goes on with and in their society. They should be given a detailed picture of the status and the functional bits of their developing chapters so that they can be aware of each and every news item doing the rounds.
- Exposure: Women should be given proper exposure at national and international level, so that they can have that "developing interest" within themselves.
- Working with Men: To strengthen their base they will definitely need the help of the opposite side. So being helpful and creating an environment where women could bring up ideas in a prompt manner, is what is expected from the opposite gender.
- Communication: Team leader explain the common goal to the team members. They explain the procedures to members such as how to communicate with one another on a daily basis or weekly basis and how to provide reports (verbal or written).

- Assignments: Leaders need to assign clear roles and responsibilities to each team member.
- Consideration: Consider each person's ideas as valuable. Be aware of person's unspoken feelings. Act as a harmonizing influence.
- Encouragement: Take time to encourage trust, cooperation and sharing of information with different women in your team and encourage listening and brainstorming.

Example: In WGHFI, teamwork allows more ideas to be brought forward through sharing of creativity and greater productivity through more helping hands and hearts.



7. Planning, Organizing and Executing an Event

The WGHFI will lead and implement many events at the Chapter, Regional and National levels.

Planning

- Discuss the agenda of the event with the team in detail.

An effective event requires a volunteer team and delegate roles. Hint: Make sure to select people who are dependable. It's best if a few of them are experienced ones.

Organizing

- Choose and book a venue
Hint: venue must have a clear stage view.
- Leader should give clear instructions to team members about venue location, time, agenda of event, and role of each member of the team.
- It is important to generate publicity about the event.

Hint: For that can take the advantage of free social networking tools and local media. For generating more publicity call a celebrity guest for the event and explain everything about the event to the celebrity guest.

Executing

- On the day of the event the entire team should reach the venue at least 2 hours before.
- First, to check everything and second to receive any guests for the event and third to see that everyone is properly seated
- Volunteers should be available to talk with and to help guests.

Close Out

- After the event, see to it that the venue is as clean as it was before the event.
- Leader must hold a meeting of all team members to know their views about the event and if there were some problem. It's important to discuss it to know whether it was due to mismanagement or something else so that it should not happen in future.

Example: Each year Hemophilia Day is on April 17th. The Women's Group will lead many of these events for their chapters. Talk with other women who have done this to learn how to plan ahead, organize your team, execute the event and close out the event.



8. Communication

Communication is the exchange of information between two or more people. Effective communication helps us better understand a person or situation and enables us to resolve differences, build trust and respect, and create environments where creative ideas, problem solving, affection, and caring can flourish. As simple as communication seems, much of what we try to communicate to others—and what others try to communicate to us—gets misunderstood, which can cause conflict and frustration in personal and professional relationships. By learning these effective communication skills, you can better connect with

your spouse, children, friends, and co-workers.

It is important to communicate well. It can help you to understand what another person is saying. It also means that they can express their own needs and concerns.

Being able to communicate well is important. There will be people from various organizations and having different ideas that we will communicate with. This includes family and different health professionals. It is helpful to think about how to manage these conversations. How do you want to share your information and with who? The people you are important to will also have their needs to share with you. You may not know how to talk to people about what is happening. If that happens, ask others for ideas.

In our haemophilia community, it is also necessary to interact and to communicate with one other so as to share information, to get guidance, and to acknowledge others about the potential activities done by us in our group or chapter.

Talking is not the only way we communicate. Sometimes sitting quietly together can be enough.

Here are 10 steps to practice becoming a good communicator:

1. Know what communication really is.
2. Have courage to say what you think.
3. Practice
4. Engage your Audience by making eye contact, using gestures, not sending mixed messages; be aware about the body language.
5. Enunciate your words, means, speak clearly and don't mumble.
6. Pronounce your words correctly, use the right words, slow down your speech.
7. Intonation of voice
8. Try to be good listener, as a Good Speaker is a Good Listener.
9. Don't over praise yourself in front of Audience.
10. Get feedback from your receiver to ensure you were properly understood during your conversation.



9. Ensuring Involvement

Involvement is the act of sharing and becoming involved in the activities of the group. An NGO or Group cannot be successful if only a few members participate. Leaders of a new group must find ways to encourage members to get involved.

Here are a few points which are important to ensure involvement:

- Invite members to meetings with plenty of advanced notice
 - Try to set up a time to conduct regular business meetings of members
- Survey the group to identify topics of general interest
 - Take time in the meetings to address key concerns
 - Organize specific initiatives. Break members into sub teams, these can include brainstorming on areas of concern.
 - Conduct periodic events (quarterly or half yearly) to ensure involvement and engagements

Involvement can also include bringing in the media to aid in providing awareness to a national or even international larger audience. Here are some steps to engage the media:

- Identify clear objectives and outcomes
- Identify stakeholders and their needs
- Prepare an action plan - Thoroughly plan targeted actions
- Find media partners among top print and electronic national media
- Prepare key messages, documents and meetings. You should become a partner of the media by providing them good quality , interesting information
- Provide media trainings for doctors and patients to speak in public about haemophilia issues
- Organise a working breakfast with the media, doctors and haemophilia patients in order to discuss about the issue and the materials prepared (key messages, press information document)
- Engage stakeholders and keep momentum
- Monitor, measure and follow up
- Keep contact with media on regular basis



10. Networking

Networking, in an NGO, is a supportive system of sharing information and services among individuals and groups having a common interest.

In an NGO's early stages, you need networking of people to bring together members and to support them by sharing information and services. Gradually, this networking among members becomes strong.

NGO's such as Hemophilia Federation (India) have various stakeholders. Stakeholders have a "stake" in what we are doing and sometimes even how we do it. Some of our stakeholders donate money such as

government or pharmaceutical companies. Some are agencies who require us to provide information so they can offer support. And many are families who have family members with bleeding disorders.

Each stakeholder has different ways they network with NGOs. To be successful we have to participate appropriately in our stakeholder networks. The capacity of organizations to participate is also important: like new and small NGOs cannot meet the cost of engaging in networking activities. Sometimes only weekends are times when we can hold meetings for networking so that everyone can attend.

For a new group or NGOs, networking should be member-driven, encouraging initiatives from members and also encouraging them to use networking strategically. There are NGOs who are in a network because they need to access information and build capacity in areas of growing importance for them. On the other hand, smaller NGOs are able to attract volunteers and paid staff through networking. We can say that networking is essential but every NGO should examine their primary needs, its member's concerns, its timing, content and format. It should also consider organizational capacity and culture and then opt for the kind of networking that is most suitable.

Examples: HFI is one of 122 NMO Partners with the World Federation of Hemophilia. NMO's represent the interests of people with haemophilia in their country. The WFH recognizes one national haemophilia organization per country as an NMO. New NMOs are recognized by vote at each WFH General Assembly.

<http://www.wfh.org/en/page.aspx?pid=1289>



11. Democracy and Transparency

"I would boycott that legislature which will not have a proper share of women members."
— *Mahatma Gandhi*

Democracy is the government of the people by the people for the people. All eligible citizens participate directly or indirectly.

In the context of NGO's, Democracy and Transparency both are of the utmost importance.

When we choose a leader in an organization we do it democratically. We can ask member's views about a particular person or ask members to suggest the name of someone who can become a leader or we can choose between 2-3 persons, either directly (by raising hands) or by voting. That will be a democratic way of choosing a leader. In this way, members will have the satisfaction of choosing their leader or participating in the event and an additional benefit is that even ordinary members will also feel involved in activities of organization.

Transparency means that anybody can see through it. When transparency is working, it is easy for others to see what and how you are operating (working) at different levels in an organization.

It is the same way if we want to start a new project or plan an event. When we ask our members for their opinion,—simply by raising hands or voting, our members will feel that they are part of decision making process in the organization.

Transparency is equally important for an organization in selection of a leader or members, in some organizations in case of promotions of staff members and it is also important in financial matters.

When money is involved, transparency is very important. How you are getting money, how much you are getting and how you are spending it, on which project you are spending more and if the organization is helping out someone financially including why and how much help you are giving.

Everything should be transparent, otherwise members will always raise objections and the trust-building will be not possible, which is not good for any organization.

Example for Transparency: The WGHFI uses distribution lists to send emails to all the women leaders. This allows all women on the distribution list to receive communication and stay informed.

Example for Democracy: The WGHFI uses voting to elect leaders.



12. Resource Mobilization

Mobilization is the process of forming a group, association or organization for the pursuit of a common goal. There are various resources which we need to start a group. They include technology, labour, capital, organizational structure, and social support. The duty of the leader or management is to mix the resources in a right proportion.

The most important resource of an organization or group is the members. Motivating participants (members) to continue to make contributions is one of the most important activities of the leaders of group or management.

Resource mobilization can be broadly defined as the process of raising support in various forms for your NGO.

It can cover the following:

- Submitting the proposals to donors for raising funds,
- Organizing fund-raising events,
- Collecting in-kind contributions such as clothes , material etc.,
- Organizing volunteer support for advocacy,
- Generating income from any project of the NGO such as a publication, etc.

A leader or manager must have the ability to see that what her/his members can do best. Some women enjoy organizing events (and they do it well). Others can manage the stage at the event or who might know how to best publicize the event. Others don't mind collecting donations and some understand how to handle the technology. A leader should mobilize her team according to their preferences and abilities to get good results.



13. Redefine Vision and Set New Targets

A good leader knows how to manage change and can motivate her team to accept and embrace change. The ability to respond to change is very important as the pace of innovation, politics, and organizational dynamics can be very rapid.

Even though a leader starts with a wonderful vision that has clarity, purpose and direction, something may occur externally or internally to the group that causes a need to redefine the vision and set new targets.

Sometimes change is required to make progress because the group is stalled and can't move ahead. Here is one method organizations may use to identify, share and implement a change in their business activities. It is called an S-T-P—which means “Situation, Target, Proposal.”

- First, someone writes down the current **Situation**.
- Next, they envision a future or “**Target Situation**” and draw it in a picture, or write it in words.
- Finally, a **Proposal** is written that states how to move from the current situation to the future or target situation.

Example: S-T-P:

Current Situation: The women in our chapter are impoverished and not able to support their family. Their husbands have haemophilia and are not able to support their family and the women do not have skills to earn money.

Target Situation: The women help one another with family care and begin a small business together by purchasing a few sewing machines and learning to sew items they can sell.

Proposal: The women make a proposal to their Women's Group Regional Chairperson requesting three sewing machines and training for 10 women so that they may earn dollars for to support their families. The proposal is accepted. The women begin their business together.



14. Caregivers

When a boy suffers, he first looks for his mother or his elder sister, even though they can't take the pain from him. But when a mother just puts his head on her lap, he forgets half of the pain, as he finds himself in the safest place in the world.

Still at remote corners of our big developing nation there are hundreds of sufferers and hundreds of mothers who still find themselves in despair at times.

Caregivers take responsibility for the patient's day-to-day care and comfort. In most cases the caregiver is a mother, a spouse, a partner or close relative of the person who has a chronic condition. In the case of haemophilic children, mothers are generally the primary caregivers.

It is very important that caregivers must have the knowledge of problems and how to handle the haemophilic family member.

- She should know in the case of different types of bleeds, what she is supposed to do.
- She should know how to help the patient with basic physical care, such as toileting, bathing, grooming and talking to the Doctor on a daily basis about the condition of patient.
- She should know how to have communication with the Doctor in case of any emergency. Communication with the patient is also very important to keep the patient happy or in positive frame of mind.
- If the PwH or CwH is not receiving any communication from anyone they can get depressed or will feel lonely as others are busy with their routine work and they feel helpless. It is very important that caregivers should get some guidance as how best to handle the PwH. As such the duties of caregivers can't be defined as they vary from one PwH to another.
- A mother, spouse or family member can be given guidance at the chapter level by organizing the session about treatment plans by Doctor or nurses.
- Some senior members of Hemophilia chapter can share their experience of handling Haemophiliac patients with younger members of chapter, here the advantage is they all (senior and younger) have the same problem—a bleeding disorder.



15. Leadership in Community Through Psychosocial Support

The following section is extracted from “Reaching Out”—A guide to Psychosocial Intervention for Person with Hemophilia and their Families. (March 2009) by Richa Mohan, M.A. M.Phil (Psychology) Psychosocial Consultant to HFI.

“A new born baby brings in joy to their parents and family members. But when a child is born with any disorder however mild it may be, it creates a psychological fear in the parents mind. They feel

angry, hurt, and remorseful and these feelings stay for a while and if left unattended then they may stay for life. These are natural reactions. But on the other hand if the parents are made aware or ‘sensitized’ to deal with the situation, things become much easier and effective to handle. And a child born such receives the proper nourishment, care and love they deserve. Same is the case with children born with bleeding disorders, a condition in which one of the clotting factors in the blood is missing. Most often referred to as a Person with Hemophilia (PWH), there are actually many types of bleeding disorders with hemophilia referring to the absence of factors VIII or IX. It is an inherited condition in most cases; it is life-long; and at present cannot be cured. The symptoms can, for some PWH, be completely corrected by the injection of a concentrate of the missing clotting factor into the vein. It is costly and 70% of those who have inherited bleeding disorders do not have access to these factors. So while bleeding disorders are not necessarily a handicap, care has to be taken to provide a healthy lifestyle and an equally healthy support system for a child to grow into a strong and positive individual. But these are also required for the healthy development of a child without a bleeding disorder. In fact the only difference between a child with a bleeding disorder and another is that one particular ‘gene’ does not work properly in the child having the bleeding disorder.

Psychosocial support (PSS) plays a very important role in giving proper guidance to the patient and his/her immediate family members. Helping patients acquire a sense of self-control and efficacy helps in enhancing their social adaptation and health. PSS also helps in removing the wrong beliefs and misconceptions associated with the disorder and creating a supportive and encouraging environment around such children.

Disabilities caused in a PWH such as amputation, disfigurement, difficulty in mobilization, depend on various factors that intervene between the occurrence of the illness and the disability. These factors can be personal such as attitudes and motivation, social setting, opportunities to participate in activities, stigma, and lack of knowledge or inability to cope with

problems. Modification of these factors is important to reduce distress and improve quality of life for any patient.

All patients do not necessarily experience these problems. There are individual differences on how people react to the illness. Some patients can accept and cope with even a severe disability whereas some cannot tolerate even a mild pain or problem.

A person with a bleeding disorder often needs blood transfusions, which involves the risk of acquiring HIV. The threat on health and uncertainty of future effects of the disease result in huge strains on PWH and their families. Counseling, education and other preventative services are required to provide emotional and social support to them. These skills need to be developed and enhanced in caregivers for comprehensive care of the person with hemophilia.”

The Women’s Group of Hemophilia Federation (India) provides ongoing training to women in their community in the areas of understanding of psychosocial needs and supportive intervention with others. It is felt that with these new skills, an entire family and community will benefit and will be able to achieve their fullest potential and participate in decisions affecting their lives and those of their communities.



16. Medical Information— Hemophilia 101

By Dr. Nita Radhakrishnan

Progress made by India in the last few decades in technology, infrastructure and governance sadly do not reflect in matters of health, especially that of women. The neglect of health by Indian women continues no matter whether she lives in the village or the city, no matter whether she is educated or not and no matter whether she is rich or poor. As health care providers, we encounter women who chose to ignore a tendency to 'bruise easily' and at

times the fact that her family members have severe bleeding for obvious reasons. This continues till the time a child is born with a severe bleeding tendency, which could have been completely prevented. We encounter women who 'tolerate' heavy menses to the verge of collapse and pass it on as 'normal' for her side of the family. We encounter women who as primary caretakers get fatigued and depressed under guilt, financial constraints and poor family support. We encounter educated women who are afraid to seek genetic counseling and opt for prenatal diagnosis just because it will project her problem into the limelight of her husband's family.

This support group has been initiated for women who are themselves suffering from bleeding and for those who are involved in the care of children and adults with bleeding disorders. In the following few pages, we shall go through the medical facts regarding early recognition, treatment and prevention of these disorders.

A. Women with a bleeding child

Diagnosis of bleeding in the baby can be quite distressing to the family especially the mother. Often we encounter a period of denial when the family refuses to get the investigations done and does not come for a planned follow up visit. Talking to the treating team especially the doctor and social worker helps in improving the situation. The diagnosis of Hemophilia, Von Willebrand Disease (VWD) or any rare bleeding disorder in a child requires care from birth till adulthood. It is important as caretakers to have a basic understanding of why the child has a bleeding tendency, what to expect at different stages of his/her life and how to prevent discomfort to the child as possible. A single person cannot manage a bleeding child effectively. Collaborating with the treating team and local hemophilia support group or hematology center is the only way to go in dealing with this situation appropriately.

Important factors in managing a baby with a bleeding disorder includes knowing the type and severity of the bleeding disorder, knowing what to anticipate at different stages in life and knowing how to manage an emergency till you get medical help. Other than obvious external

bleeding from cuts and wounds, the other main sites of bleeding include bleeding into muscles and joints, bleeding inside the intestines and urinary tract as well as in the head. A young child who is limping or refusing to use a limb, crying on being lifted up or keeping a limb flexed should be taken seriously. In such conditions, the child should be taken to the nearest treatment center as fast as possible and at times factor concentrates may be provided at home if available. Symptoms that indicate bleeding in the brain such as loss of consciousness, repeated vomiting, drowsiness, headache or confusion should prompt visit to the nearest hospital. It is worthy to note that at times following a fall child may be 'apparently well' for few hours to a day before symptoms start. Parents and treating team should be aware that bleeding may be delayed in some cases and patients should not be dismissed off even if there are no immediate symptoms. Prompt treatment always helps as bleeding will stop faster and less blood will accumulate at the site.

Prevention of bleeding is vital. Restraints to prevent fall from bed, especially in an infant who has just started rolling over, to prevent fall from a staircase or a vehicle is of utmost importance. Sharp objects such as knives, scissors, nail cutters, sharp toys should be out of the reach of such children. Intramuscular injections should be avoided and trained professionals should administer vaccinations after taking adequate precautions. Drugs that increase the bleeding tendency such as anti-inflammatory agents should be avoided in these children. General first aid measures such as antiseptics, adhesive bandage, elastic bandage and splints and if possible tranexemic acid tablets and factor concentrate should be available at home always.

School personnel must be educated regarding recognition of common bleeding episodes and their management. In case of bleeding from the nose, firm continuous pressure should be applied under the bridge of the nose with fingers/cold cloth for at least 20 minutes. In children who bleed from cuts on lips/gums, again firm pressure with cold cloth, sucking on ice and local application of tranexemic acid should be done. In case of a joint swelling suspicious of a joint bleed, it is advisable to keep the limb immobile and protect it using splints that can be made using easily available household items such as wooden scales, steel or plastic spoons. Ice wrapped in a hand towel may be applied for 5-7 minutes with a gap of 5 minutes in between intermittently to alleviate the pain. Wrapping the limb using elastic bandage and elevating the limb using pillows/cushions should be encouraged to reduce the bleeding as well the swelling in the limb.

Over the past few years, there has been a change in the factor replacement principles in hemophilia from *treating* episodes of bleeding to *preventing* bleeding with factor prophylaxis. Prophylaxis is a treatment regimen where factor concentrates are infused 2-3 times in a week in order to raise the factor level and this prevents most bleeding episodes. Possibility of offering prophylaxis to your child may be discussed with the treating team and decided there upon. In case of bleeding disorders other than hemophilia appropriate factor concentrates or plasma products may be used as per the availability. In few patients with severe deficiencies who are at high risk of intracranial bleeding viz. factor XIII deficiency, prophylaxis may be advised.

In patients' receiving home treatment as part of treatment or prophylaxis, it is important to remember that infusions must be done in a sterile environment. Cleaning hands prior to injections, wearing gloves prior to injections, using alcohol swabs to clean the area of needle insertion, discarding the needle safely after use and never reusing or sharing a needle should be strictly adhered to. In case finding a vein is extremely difficult for repeated infusions, central venous access is used in developed countries. The importance of regular exercise and physiotherapy strengthening the muscles cannot be undermined. Physical activities that keep the muscles strong and joints healthy not only prevent reduce bleeding by withstanding trauma, but also improves the self-esteem and social acceptance of the child.

Maintaining the details of treatment received by the child is extremely useful in the long run. The dose of factor received, number of exposure days and similar details are recorded by most hemophilia treatment centers. Hemophilia Federation of India has 72 chapters across the country that has facilities for diagnosing and treating hemophilia. Coordinating with the local hemophilia treatment center will go a long way in managing your child effectively, keeping him free of bleeding to a great extent and giving him a good quality of life. Details regarding your nearest hemophilia treatment center is available at <http://www.hemophilia.in/index.php/2013-03-08-08-43-53/hemophilia-treatment-centers>

B. Women with bleeding

Bleeding in women has been underestimated for long due to unawareness and misdiagnosis. Von Willebrand disease, rare bleeding disorders and even bleeding in carriers of hemophilia are being recognized more commonly in women. Undiagnosed bleeding disorder can often be disastrous as they lead to heavy menstrual bleeding, problems during pregnancy and childbirth, bleeding following surgical procedures and other medical problems. Symptoms that demand further evaluation in women include heavy menstrual bleeding, easy bruising, recurrent nosebleeds and history of joint or muscle bleeding and other severe bleeding. Heavy menstrual bleeding includes bleeding lasting for more than 7 days, bleeding that limits daily activities, passing blood clots and receiving treatment for anemia following bleeding. Very often heavy menstrual periods in women are considered to be normal especially if there are other family members who have similar complaints. It is very important for women to understand what is an abnormal period. Young women have irregular periods that are often heavy because of anovulatory cycles. However in women who continuously have heavy periods especially since the onset of menarche need evaluation and help with managing their periods. Often in girls diagnosed with VWD, rare coagulation disorders and platelet function disorders oral contraceptive pills are started in order to reduce the heavy flow. Also supportive care measures such as tranexamic acid, appropriate management of pain during menstruation and iron supplements to correct anemia help improve the quality of living significantly. Also, women who are carriers of hemophilia should be adequately evaluated early in life and closely monitored during surgery. Fortunately, Factor VIII and von Willebrand factor levels increase during pregnancy and do not cause much trouble during childbirth. Factors XIII, IX, V and II remain at the same level during pregnancy and hence these women may need coagulation

factors/plasma products during childbirth in order to avoid severe bleeding. All pregnancies in women with underlying bleeding disorders should be considered high risk. Invasive monitoring of the fetus, instrumental delivery using forceps or vacuum and intramuscular injections to the newborn should be avoided.

C. Prevention of bleeding disorders

Prevention of the birth of a child with a severe bleeding disorder is a reality today and is worth considering by all couples at risk. Pre pregnancy counseling should be offered to all women who are carriers of hemophilia, who are affected with von Willebrand disease and who have other affected family members with rare bleeding disorders. Genetic diagnosis should preferably be established prior to pregnancy as it hastens the prenatal diagnosis. Chorionic villus sampling and umbilical blood sampling are techniques used which helps in isolating the DNA of the fetus. Further the fetus can be tested and depending on the result further course of action can be chosen.

To conclude, the diagnosis of bleeding disorder affects every part of an individual's life and the lives of his/her family members. Ongoing education of patients and caregivers and collaboration of the family with the treating team, support groups, teachers, prospective employers should be seriously considered in our country to ensure a brighter future for these children.

Suggested reading:

1. World Federation of Hemophilia (Online) 2012. Available from <http://www1.wfh.org/publication/files/pdf-1471.pdf>
2. Price VE, Hawes SA, Chan AK. A practical approach to hemophilia care in children. Paediatr Child Health. 2007; 12(5): 381-3.
3. World Federation of Hemophilia (Online) May 2012. Available from <http://www.wfh.org/en/page.aspx?pid=637>
4. Steps for Living. Education for all life stages. National Hemophilia Foundation © 2013. Available at <http://www.stepsforliving.hemophilia.org/next-step-kids/treatment-kids/self-infusion-kids>



17. Physical Therapy Support at Home

Can Physical Activity/Exercise Help People With Bleeding Disorders?

Yes! Physical activity and exercise are important for people with bleeding disorders. They help develop strong muscles and bones, which can help stabilize joints and prevent injury and bleeds.

Throughout their life, participating in activities will help prepare him or her to join peers in recreational and organized sports. It will also build self-esteem by

develop the same skills as his or her friends.

Sports and games can be an important lifetime hobby. The physical, social, and emotional benefits gained should outweigh most of the concerns about participation.

As a part of a lifetime of physical activity, caregivers should encourage their family member to participate in ongoing physical fitness and normal neuromuscular development activities. Special attention should be paid to muscle strengthening, coordination, general fitness, physical functioning, healthy body weight, and self-esteem.

Bone density may be decreased in people with hemophilia. For PwH with significant musculoskeletal dysfunction, weight-bearing activities that promote development and maintenance of good bone density should be encouraged, to the extent their joint health permits.

The choice of activities should reflect an individual's preference/interests, ability, physical condition, local customs, and resources. Non-contact sports such as swimming, walking, golf, badminton, archery, cycling, rowing, sailing, and table tennis should be encouraged. High contact and collision sports such as soccer, hockey, rugby, boxing, and wrestling, as well as high-velocity activities such as motocross racing and skiing, are best avoided because of the potential for life-threatening injuries, unless the individual is on good prophylaxis to cover such activities.

Organized sports programs should be encouraged as opposed to unstructured activities, where protective equipment and supervision may be lacking.

The patient should consult with a musculoskeletal professional before engaging in physical activities to discuss their appropriateness, protective gear, prophylaxis (factor and other measures), and physical skills required prior to beginning the activity. This is particularly important if the patient has any problem/target joints.

Target joints can be protected with braces or splints during activity, especially when there is no clotting factor coverage. Activities should be re-initiated gradually after a bleed to minimize the chance of a re-bleed.



18. Intimacy

As a mother or caregiver to a young person with bleeding disorder, a parent should not assume their child will always be under their care. A goal would be to prepare them to become a partner with another adult in a loving and caring relationship.

As a spouse who might also be the primary caregiver to a partner with a bleeding disorder, you should expect that you will be able to create an intimate relationship that includes sexual activity with your partner. Haemophilia does not generally affect sexual activity, although there is a slight risk of developing minor bruising of the genitals in those with more severe haemophilia.

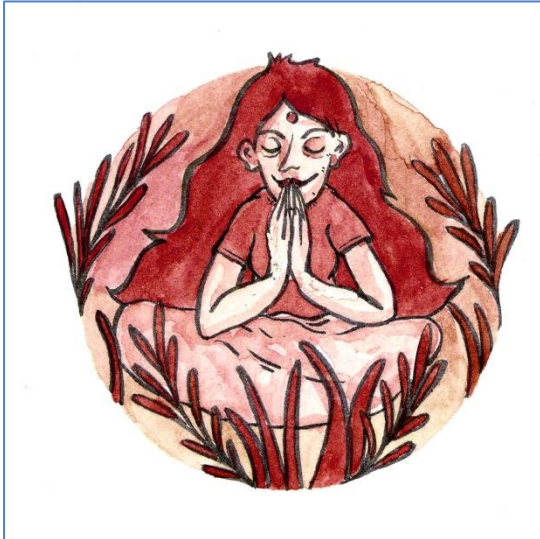
Following is extracted from: <http://www.hemophiliabangalore.org/faq.html>

“If you live with someone who has chronic pain, some people may mistakenly assume they’re not interested in sex. People with chronic pain can and do have satisfying sexual relationship. Satisfying sex with your partner can help you both be more accepting to conditions, enhance confidence in your own sexuality and help you feel better physically. A satisfying sexual relationship depends on open communication with your partner. It is important to find a time and private place, free from distractions, to talk about the sexual needs, distress, and ideas you both have.

Think about trying something new: this could provide fresh excitement, comfort, and pleasurable intimacy. Encourage new ideas in one another, without pressing or rushing. For example, you might consider creating a new romantic setting, changing the place where you usually make love, or discovering new and pleasurable ways to touch and hold one another. Consider this an adventure well worth your time and patience.

Let your partner know what feels good to you: you know what you find comfortable, exciting or painful. Your partner knows what you feel only when you tell him or her. Words are likely to be clearer than smiles or sighs. Take turns giving each other a gentle massage. This is a good way to learn to talk about body feelings. When your partner’s hand gets near a painful area, simply redirect it. Continue to share your feelings through words. Have clear, pre-sex signals to let your partner know if you experience severe pain. A signal can enable you to continue your lovemaking on a positive level rather than bringing it to an abrupt end because you both feel anxious.

Talking about your feelings will end the guesswork between you and your partner. Support and new understanding which can come from talking may make you feel better than you have ever felt before. Always let your partner know when something really feels good-this is the must. There are many satisfying ways, other than intercourse, to make love and to have your body respond to sexual stimulation. Some of these may be familiar to you; others less so. All are normal, natural expressions of human sexuality. These alternate sexual activities can be a welcome solution when your partner is having pain.



19. Spirituality

Spirituality is very personal and each person derives strength from it. It has an impact on his/her persona in many ways.

Spirituality helps people gain inner strength to be able to identify and go over their obstacles.

A contrasting topic is that of religion which is a social group.

HFI, along with WGHFI is wholly a secular formation independent of any religion, which in turn reflects its unity in diversity. And how every individual associated

with HFI/WGHFI is proud about that very fact; whether he/she is a Christian/Muslim/ Hindu/ Sikh/Jain/Budhist/Jewish.

The Merriam-Webster dictionary defines spirituality as the quality or state of being concerned with religion or religious matters : the quality or state of being spiritual. Spirituality and religion are often understood as same but there is a pretty defined difference between the two: Religion is a specific set of organised beliefs and practices, usually shared by a community or group whereas Spirituality is more of an individual practice and has to do with having a sense of peace and purpose. It also relates to the process of developing beliefs around the meaning of life and connection with others.

Therefore, there is no one definition, but in general, spirituality:

- is something everyone can experience
- helps us to find meaning and purpose in the things we value
- can bring hope in times of suffering and loss
- encourages us to seek the best relationship with ourselves, others and what lies beyond.

These experiences are part of being human - they are as clearly present in people with bleeding disorders, disability and other conditions as they are in anybody else.

Chronic disorders and associated life-altering events often lead people to question the meaning and purpose of life. "Why? Why me? Why now?" and they seek answers based on their faith, belief and other values. In this sense, spirituality provides the foundation and support that enables them to move from conflict and brokenness to a sense of wellbeing and wholeness. It helps a person gain insight, self-knowledge, and a heightened understanding of life.

The relationship between spirituality and health is historical, intellectual and practical, and it has now emerged as a significant field in healthcare research, clinical practice and training. We hear them repeated in focus groups, in patients' writings and stories: When people are challenged by something

like a serious illness or loss like bleeding disorders, they frequently turn to spiritual values to help them cope with or understand their illness or loss. Many women, PWH and their families expressed seeking solace and comfort when they visited religious places, spiritual gurus, practised yoga and meditation, do prayers, or just chanted at home.

Following are a wide range of the Spiritual Practices as reported by people with bleeding disorders in different settings.

- belongs to a faith tradition and take part in services or other activities with other people
- take part in rituals, symbolic practices and other forms of worship
- goes to pilgrimage and retreats
- spend time enjoying nature
- give oneself in acts of compassion (including work, especially teamwork)
- spend time in meditation, deep reflection or prayer
- follow traditions of yoga, Tai Chi, meditation and similar disciplined practices
- read scripture
- listen to singing and/or playing sacred music, including songs, hymns, psalms and devotional chants
- spend time in contemplative reading (of literature, poetry, philosophy etc.)
- appreciate the arts
- be creative - painting, sculpture, cookery, gardening etc.
- make and keep good family relationships
- make and keep friendships, especially those with trust and intimacy
- join in team sports or other activities that involve cooperation and trust

In India both National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore and All India Institute of Medical Sciences (AIIMS), are doing researches on Yoga and practice and effects on the patients. AIIMS conducted a study at the patients who recovered from cancers has suggested that yoga and meditation improve the body's immune system. A steadily building body of research shows that spiritual practices and beliefs support health.

Therefore it can be concluded that spiritual perspectives and practices can provide a context wherein anxieties about physical and mental functioning may be faced, felt, and understood. Patients who are spiritual may utilize their beliefs in coping with illness, pain, and life stresses. Some studies indicate that those who are spiritual tend to have a more positive outlook and a better quality of life.



20. General Care and Management of Hemophilia

World Federation of Hemophilia Guidelines for the Management of Hemophilia – WFH 2012

Following sections are excerpts from..... General Treatment Guidelines

<http://www.wfh.org/en/resources/wfh-treatment-guidelines>

- a. Prophylactic factor replacement therapy
- b. Home Therapy
- c. Monitoring health status and outcome
- d. Pain Management
- e. Dental Care and Management

20a. Prophylactic Factor Replacement Therapy

Prophylaxis is the treatment by intravenous injection of factor concentrate in order to prevent anticipated bleeding. Prophylaxis does not reverse established joint damage; however, it decreases frequency of bleeding and may slow progression of joint disease and improve quality of life. Prophylaxis as currently practiced in countries where there are no significant resource constraints is an expensive treatment and is only possible if significant resources are allocated to hemophilia care. However, it is cost-effective in the long-term because it eliminates the high cost associated with subsequent management of damaged joints and improves quality of life.

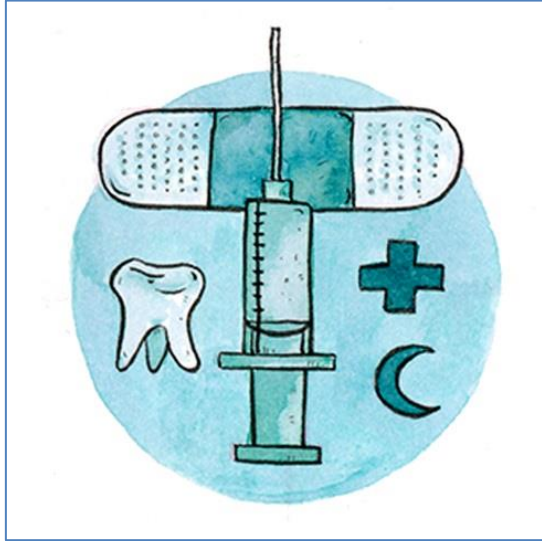
In countries with significant resource constraints, lower doses of prophylaxis given more frequently may be an effective option. Prophylaxis is best given in the morning to cover periods of activity.

20b. Home Therapy

Teaching should focus on general knowledge of hemophilia; recognition of bleeds and common complications; first aid measures; dosage calculation; preparation, storage, and administration of clotting factor concentrates; aseptic techniques; performing venipuncture (or access of central venous catheter); record keeping; proper storage and disposal of needles/sharps; and handling of blood spills. A certification program is helpful.

Patients or parents should keep bleed records (paper or electronic) that include date and site of bleeding, dosage and lot number of product used, and adverse effects.

Infusion technique and bleed records should be reviewed and monitored at follow-up visits.



Home care can be started with young children with adequate venous access and motivated family members who have undergone adequate training. Older children and teenagers can learn self-infusion with family support.

The venous access device must be kept scrupulously clean and be adequately flushed after each administration to prevent clot formation.

20c. Monitoring Health Status and Outcome

Regular standardized evaluation at least every 12 months can identify new or potential problems in their early stages so that treatment plans can be modified.

The following should be evaluated and education should be reviewed and reinforced:

- Issues related to venous access
- Issues related to hemostasis (bleed record)
- Use of products for replacement therapy and the response to them
- Musculoskeletal status: impairment and function through clinical assessment of joints and muscles, and radiological evaluation annually or as indicated
- Transfusion-transmitted infections: commonly HIV, HCV, and HBV, and others if indicated
- Development of inhibitors
- Overall psychosocial status
- Dental/oral health

20d. Pain Management

Acute and chronic pain are both common in patients with hemophilia.

Pain caused by venous access

- In general, no pain medication is given.
- In some children, application of a local anesthetic spray or cream at the site of venous access may be helpful.

Pain caused by joint or muscle bleeding

- While clotting factor concentrates should be administered as quickly as possible to stop bleeding, additional drugs are often needed for pain control.
- Other measures include cold packs, immobilization, splints, and crutches.

Post-operative pain

- Intramuscular injection of analgesia should be avoided.

- Post-operative pain should be managed in coordination with the anesthesiologist.
- Initially, intravenous morphine or other narcotic analgesics can be given, followed by an oral opioid such as tramadol, codeine, hydrocodone, and others.
- When pain is decreasing, paracetamol/acetaminophen may be used.

Pain due to chronic hemophilic arthropathy

- Chronic hemophilic arthropathy develops in patients who have not been adequately treated with clotting factor concentrates for joint bleeding.
- Treatment includes functional training, adaptations, and adequate analgesia.
- Other NSAIDs should be avoided.
- When pain is disabling, orthopedic surgery may be indicated.
- Patients with persisting pain should be referred to a specialized pain management team.

20e. Dental Care and Management

1. For persons with hemophilia, good oral hygiene is essential to prevent periodontal disease and dental caries, which predispose to gum bleeding.
2. Dental examinations should be conducted regularly, starting at the time the baby teeth start to erupt.
3. Teeth should be brushed twice a day with a medium texture brush to remove plaque deposits.
4. Dental floss or interdental brushes should be used wherever possible.
5. Toothpaste containing fluoride should be used in areas where natural fluoride is not present in the water supply. Fluoride supplements may also be prescribed if appropriate.
6. An orthodontic assessment should be considered for all patients between the ages of 10–14 in order to determine if there are any problems associated with overcrowding, which can result in periodontal disease if left untreated.
7. Close liaison between the dental surgeon and the hemophilia team is essential to provide good comprehensive dental care.
8. Treatment can be safely carried out under local anesthesia using the full range of techniques available to dental surgeons. Infiltration, intrapapillary, and intra-ligamentary injections are often done under factor cover (20-40%) though it may be possible for those with adequate experience to administer these injections without it.
9. Treatment from the hemophilia unit may be required before an inferior alveolar nerve block or lingual infiltration.
10. Dental extraction or surgical procedures carried out within the oral cavity should be done with a plan for hemostasis management, in consultation with the hematologist.
11. Tranexamic acid or epsilon aminocaproic acid (EACA) is often used after dental procedures to reduce the need for replacement therapy.
12. Oral antibiotics should only be prescribed if clinically necessary.
13. Local hemostatic measures may also be used whenever possible following a dental extraction. Typical products include oxidized cellulose and fibrin glue.
14. Following a tooth extraction, the patient should be advised to avoid hot food and drinks until normal feeling has returned. Smoking should be avoided as this can cause problems

with healing. Regular warm salt water mouthwashes (a teaspoon of salt in a glass of warm water) should begin the day after treatment and continue for five to seven days or until the mouth has healed.

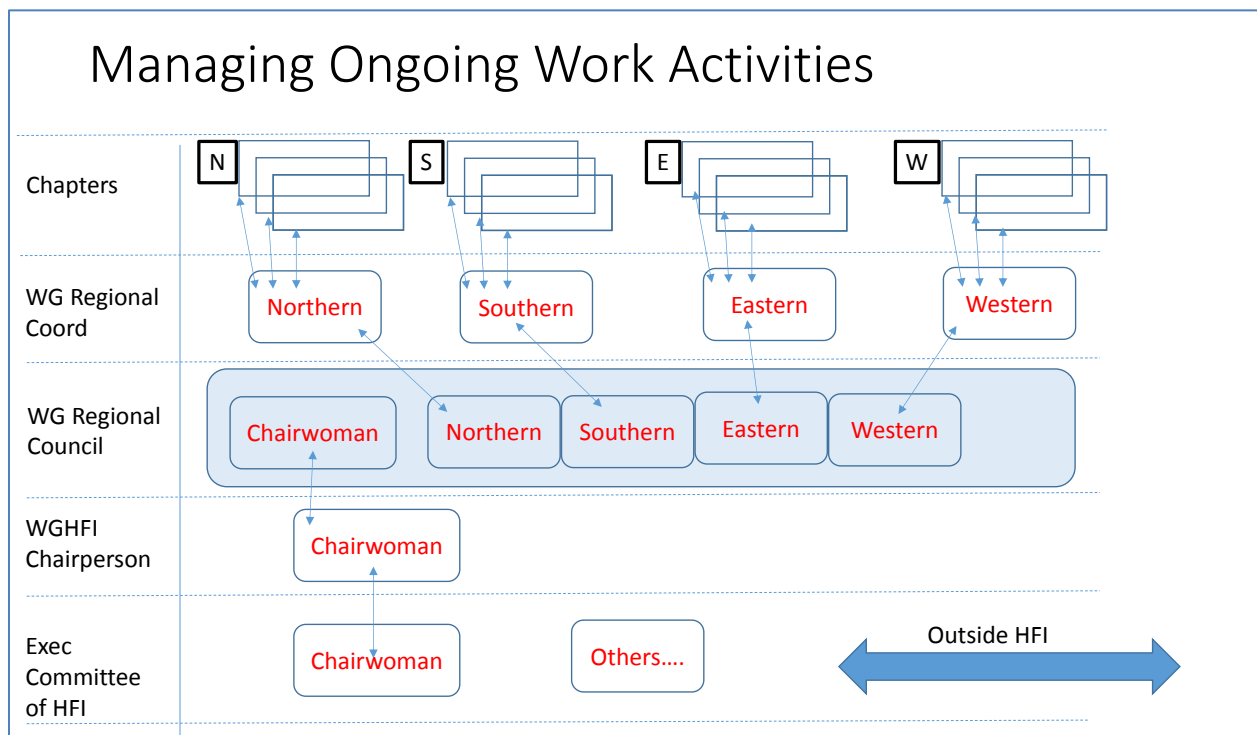
15. Prolonged bleeding and/or difficulty in speaking, swallowing, or breathing following dental manipulation should be reported to the hematologist/dental surgeon immediately.
16. Non-steroidal anti-inflammatory drugs (NSAIDs) and aspirin must be avoided.
17. An appropriate dose of paracetamol/acetaminophen every six hours for two to three days will help prevent pain following an extraction.
18. The presence of blood-borne infections should not affect the availability of dental treatment.
19. Prevention of bleeding at the time of dental procedures in patients with inhibitor

21. Business Processes and Diagrams

21.1 Ongoing Managed Business Processes

The WGHFI has ongoing work that may or may not be a part of a project. As the organization grows and takes on more responsibilities, this work will increase. As a volunteer organization, each new area of work must include a serious consideration as to how the ongoing work will be managed. One too many projects can put an entire organization into chaos.

Ongoing activities require skills in project management, leadership and good management practices. The arrows pointing both ways in the picture below indicate that communication must be ever present going in and out everywhere.

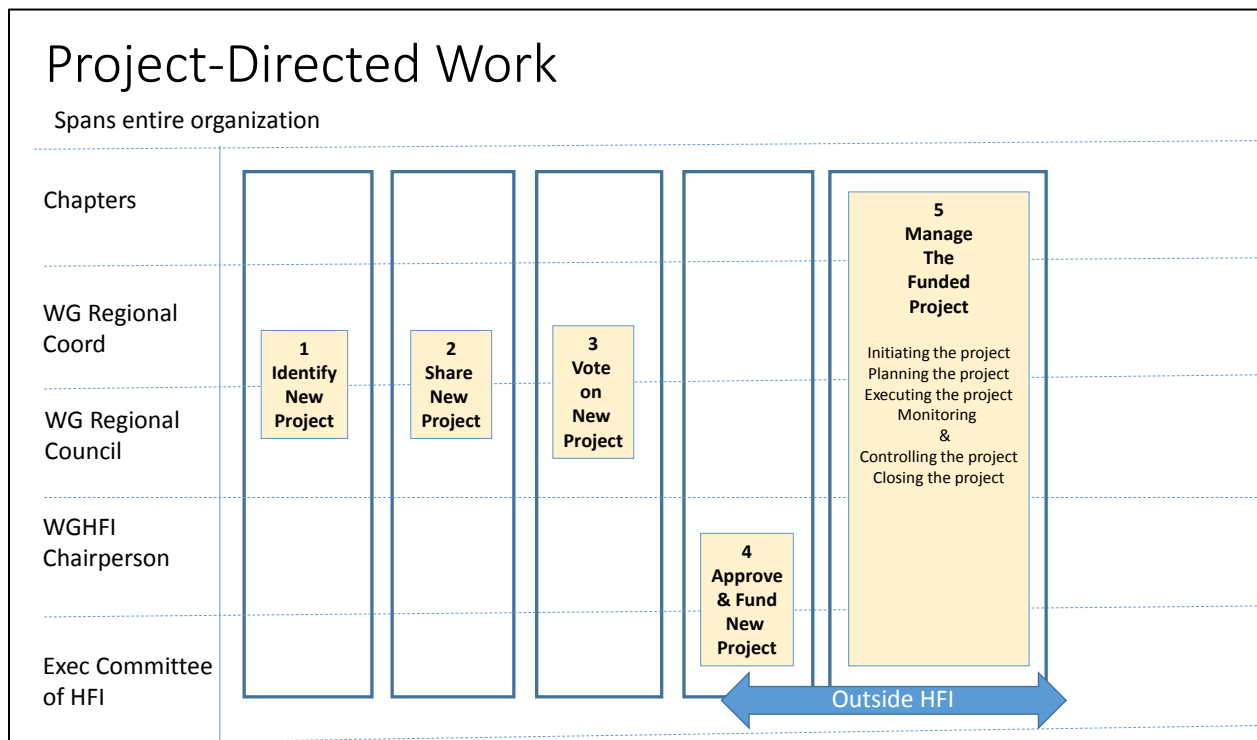


21.2 Project-Directed Business Processes

The WGHFI manages project-directed work. First it goes through a series of steps to take it through the organization; identify, share, vote, approve and fund.

Every project has a beginning date (of the project) and an end date (of the project). It requires use of project management practices, management practices and of course leadership practices.

As shown below, a project must be first approved and authorized through the HFI. The project may have a funding sponsor such as a pharmaceutical company or a charitable organization. There would be a written contract that includes requirements that must be fulfilled by certain dates. Once approved, the work to manage the project must be carefully executed to ensure a successful completion on time and to the expectation of the funding sponsor's. A happy sponsor is likely to give a good recommendation to others who are considering our project proposals and they may even consider funding future work.



Information Assets

Spreadsheets

Annual Budget
Quarterly Budget and actual expenditures

Project Budget (one for each project)
Project Budget with actual expenditures

Schedules

Annual Schedule with key milestones and events
Quarterly Detail schedules showing progress

Project Schedule (one for each project)
Project Detail schedule showing progress

Tables / Columnar Data

Roster of names, mailing addresses, phone and email address
Distribution Lists for emails and mailings
Voting items and voting results
List of organization issues
List of chapter women's issues

Details follow to better describe scenarios for each of the business process steps:

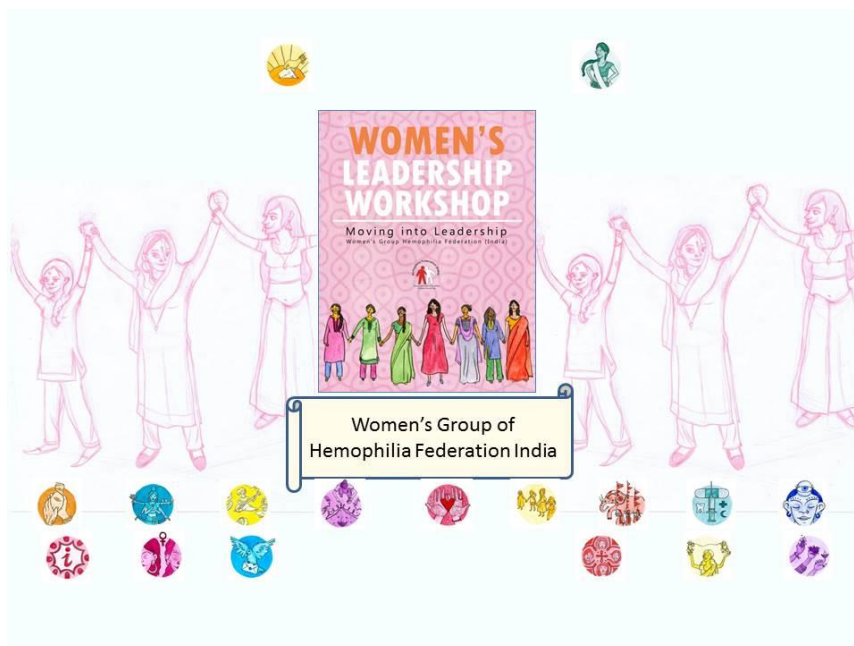
Identify

Share

Vote

Approve

Fund



21.2.1 Project-Directed Business Processes—Identify

The WGHFI has project-directed work. It has a beginning date (of the project) and an end date (of the project). It requires use of management practices, project management practices, as well as leadership practices.

We will use these processes to describe project-directed work:

- Identify
- Share
- Vote
- Fund
- Report

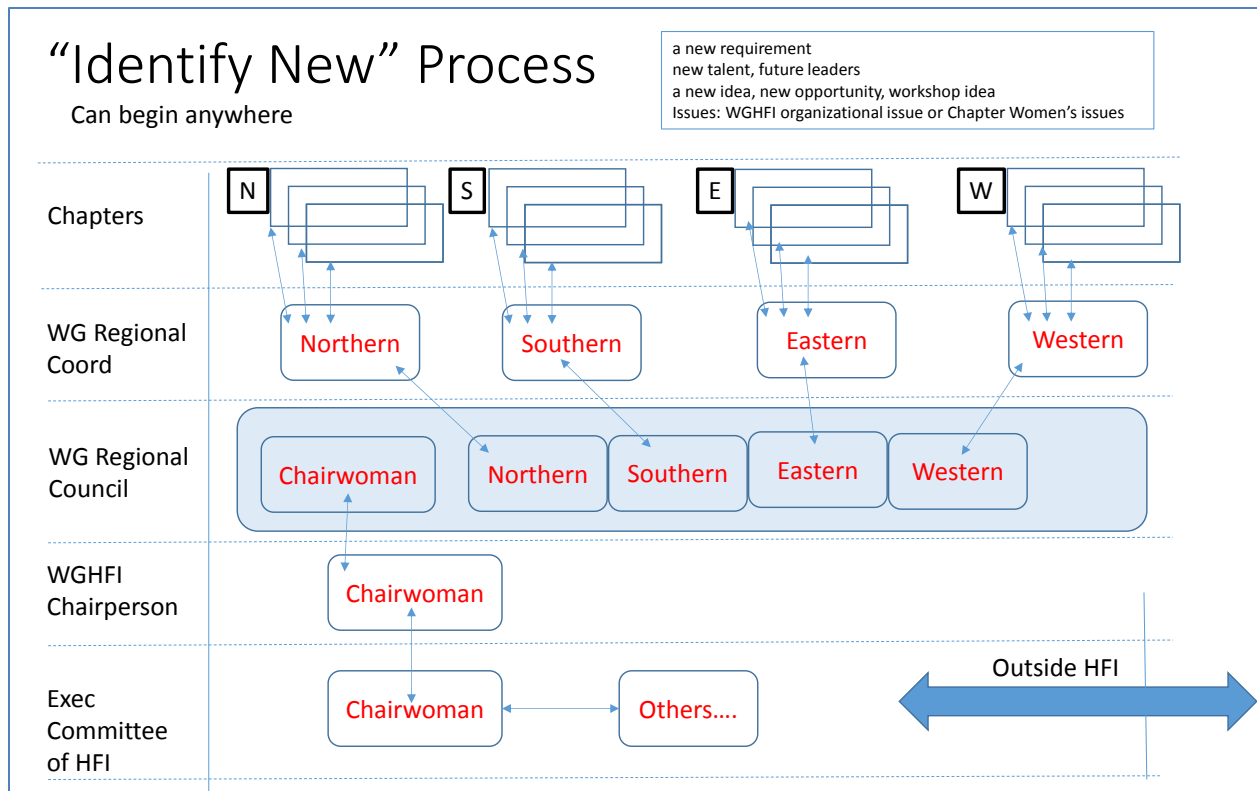
*

Identify is the first step in beginning an idea or a project. The WGHFI uses this process for the following areas:

Identify:

- a new requirement
- new talent
- a new idea, area of opportunity or workshop idea
- future leaders
- issues—an organizational issue or Chapter Women’s issues

Following is a description of each area.



Identify a new requirement

Identify a new requirement is something we must do because:

1-of an internal HFI event such as a change in operating rules, or schedule, or events.

Example: The annual HFI meeting may have more people in attendance than originally planned and we need to find dollars for additional printing of our flyers and booklets. They may also decide we need to find funding to help them support a campaign that includes mailing our booklets to other countries to spread the word of our good work.

2-a new source of funding exists where we might be able to receive dollars if we apply.

Example: The HFI exec committee members may find opportunities for funding new projects through grants or word of mouth with others. This may occur outside our normal annual funding cycle and there may even be a short timeframe where we are asked to develop a proposal. When we take on this opportunity we also take on the requirements to fulfill the grant requested activities and deliverables.

3-an external event such as a national activity, a weather issue, or a local issue that tells us we should do things differently or at a different time.

Example: A national organization of women spread across the country may have needs at specific locations that come to our attention such as increased need for safety of our women members due to local issues and as a result we need to request male members to accompany them in transit. Also it may happen that events are cancelled due to weather or road issues.

4-a change in leadership who wishes us to re-think something or to accomplish different objectives.

Example: Whether it is at the chapter, region or national level, when a new leader is elected, they should have the opportunity to ask pertinent questions about future commitments and offer guidance or course correction for those activities.

Identify new talent

Talent is important to pay attention to because volunteers generally only stay a short while. It is tiring to volunteer and do all that is necessary to manage your life, especially for those of us in the hemophilia community.

Identifying new talent includes:

- A new woman in our community
- A young woman who is related to our community
- A professional woman advisor
- A person who is a specialist

Following is a description of each.

*

A new woman member of our community with a newly diagnosed family member.

- Consider inviting her to events.
- Consider having a welcome person to talk with her individually and check on them to find out her needs and interests.
- A reminder that every leader needs followers so enlisting their ideas as a new person brings new light and insight into our work.

A young woman who is either a family member, or a bleeder.

- Consider inviting her to activities
- See if you can find out what her interests are
- A reminder that young men have a Youth Group, but we do not have a separate group for Young Women so we need to make sure to bring them into our activities.

A professional woman advisor

It is helpful to have professional women available to help us with issues and to take an interest in the work we do. They can offer new ideas, opportunities and we should include them in opportunities to speak with our group when we have workshops or planning activities. Identify areas where we need guidance and as these women are made known to us, bring their name to the Regional Council for consideration.

A person who is a specialist

We need help getting our work done. If you look at what we could accomplish, we have many helping hands not yet identified. The specialists at this time could be men or women and over time, they will train women in our group to take on these roles. At the current time we do not have enough women in our community who have the skills to fill all the jobs that need to be done.

Photographer, writer (for reports), writer (for newspaper), spokesperson (for radio stations), speaker (for awareness activities), website support, telecommunications (to help others with Skype and Google Chat and Telecons), data collection of information by interviewing individuals, computer data analyst to create spreadsheets for reports, meeting coordinator, logistics coordinator for events, artist for posters ... and the list goes on and on.

Identify new idea or new opportunity

A new idea or new opportunity is not constrained in any way. It can be something as simple as a suggestion.

A common business example is: “We can save money by booking travel flights early.”

The WGHFI is a very unique element of the HFI in that we represent the women’s roles and perspectives and we are working within an established male community.

We are women with bleeding disorders, women who carry genetic issues (with or without symptoms of excessive bleeding). We are women family members of others, mostly male, who have bleeding disorders, including mothers, wives, sisters, cousins and friends.

We have something the men don’t have—a very big world-wide issue called women’s empowerment. As such, we should have our eyes wide open for opportunities in the area of women empowerment and enlist women motivational speakers and other women to join us at our meetings.

We should also be willing to look for grant and funding opportunities in areas of women empowerment to help us spawn more projects, scholarships, and travel to conferences.

We should offer ideas for workshops such as topics of interest, learning needs, icebreaker games, or favorite speakers.

Identify Future Leaders

It has been said that anyone can learn to be a manager—that anyone can take enough training classes, read the process literature, learn the computing tools and enlist help from willing workers.

But leadership comes from within—from the heart. It is not learned, it just exists and in few people. You know it when you see it. You recognize a leader as soon as you see them and hear them speak the very first time.

Be on the lookout for these people. We are creating a new women's organization that is inside an established men's organization, and with the help of young men. Some of the WGHFI Leaders will be women, some will be men and others will be young men.

Identifying leaders by name must be done to ensure a new generation of individuals are being given adequate training and leadership opportunities and projects to manage. This can begin at the Chapter level where established women leaders mentor another person.

- Each Region Coordinator must have a person who is their backup who can take over as Region Coordinator at any time.
- Each Region Coordinator must have a list of new leaders in training, giving them opportunities for leadership assignments in their region over a 3 year span of time.
- Each Region Coordinator must offer an annual request for new leaders from each Chapter. From this list, selected Candidates will be given opportunities to speak and take on assignments at the Chapter level.

Identify Organization and Women's Issues

Identifying issues are an important part of any organization. It helps us see problems that are blocking our progress and points to areas in need of improvement.

Organizational Issues

These issues are welcome at any time and will be logged into the WGHFI Issues log. They will be reviewed on a periodic basis by the Regional Council.

An issue should be well understood by the Regional Coordinator so that she can represent the issue if it is discussed at the Regional Council.

An organizational issue should be resolved at the appropriate level, if possible (Chapter at the Chapter level and so forth). If it needs to be escalated, it should be brought to the WG Regional Coordinator who will take it to the Regional Council.

The information to take an issue forward is best done if there is a proposal for resolution in mind.

Here is an example using an S-T-P (Situation, Target, Proposal) framework.

- Situation: We have 12 Chapter women who are at 12 different Chapters and they would like to participate in psych-social training but their Chapters don't offer sessions.
- Target: All women who wish to attend psycho-social training are given an opportunity to do so.
- Proposal: Additional funds are added to travel budget to allow women from remote chapters to travel, with an escort, to the closest Chapter for training.

Chapter Women's Issues

Identifying chapter women's issues are a critical part of the work we do as the WGHFI. It is likely that these issues span not just one woman in our community, but many. Understanding the issue, the reason for the issue and creating ways to address the issue are key the success of our group.

Chapter women's issues are welcome at any time and will be logged into the WGHFI Chapter Women's Issue Log. They will be anonymous in nature, not pointing to any one woman but keeping in mind good privacy practices. They will be reviewed periodically by the Regional Council to assess if they are resolved or need additional attention.

21.2.2 Project-Directed Business Processes—Share

Sharing is similar to transparency in an organization. It allows knowledge and information to be spread and it creates an atmosphere of trust.

We have project-directed work. It has a beginning date (of the project) and an end date (of the project). It requires use of project management practices, as well as leadership practices.

We will use these processes to describe project-directed work:

- Identify
- **Share**
- Vote
- Fund
- Report

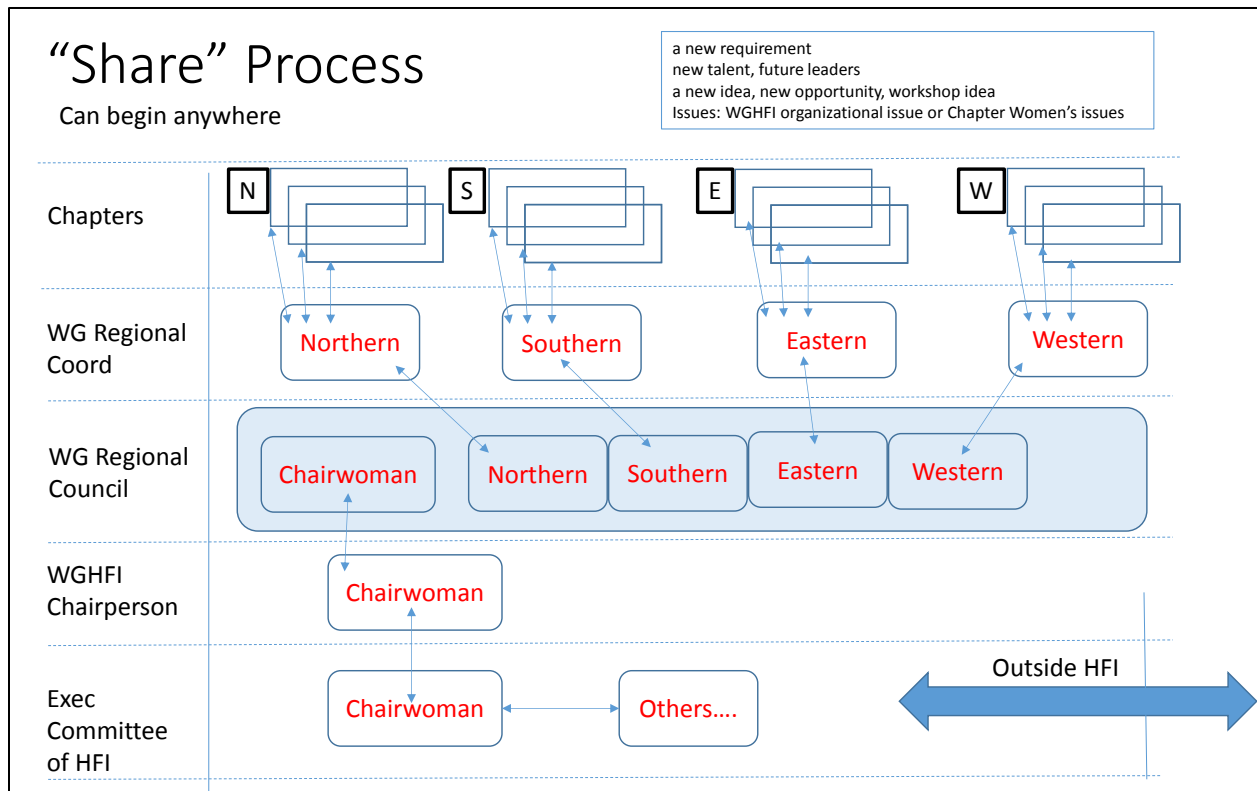
*

Share is the second step in beginning an idea or a project. The WGHFI uses this process for the following areas:

Sharing:

- a new requirement
- new talent
- a new idea, opportunity or workshop idea
- future leaders
- an issue—organizational or women's issue

Following is a description of each area.



Share a new requirement

Sharing a new requirement is something we must do because:

1-of an internal HFI event such as a change in operating rules, or schedule, or events.

Example: The annual HFI meeting may have more people in attendance than originally planned and we need to find dollars for additional printing of our flyers and booklets. They may also decide we need to find funding to help them support a campaign that includes mailing our booklets to other countries to spread the word of our good work.

*In this example, it should be shared **throughout the organization** so that everyone involved in planning can have the correct information.*

2-a new source of funding exists where we might be able to receive dollars if we apply.

Example: The HFI exec committee members may find opportunities for funding new projects through grants or word of mouth with others. This may occur outside our normal annual funding cycle and there may even be a short timeframe where we are asked to develop a proposal. When we take on this opportunity we also take on the requirements to fulfill the grant requested activities and deliverables.

*In this example, it should be shared **throughout the organization** so that everyone involved in planning can have the correct information.*

3-an external event such as a national activity, a weather issue, or a local issue that tells us we should do things differently or at a different time.

Example: A national organization of women spread across the country may have needs at specific locations that come to our attention such as increased need for safety of our women members due to local issues and as a result we need to request male members to accompany them in transit. Also it may happen that events are cancelled due to weather or road issues.

*In this example, it should be shared throughout the **necessary local groups** so that everyone involved in planning can have the correct information.*

4-a change in leadership who wishes us to re-think something or to accomplish different objectives.

Example: Whether it is at the chapter, region or national level, when a new leader is elected, they should have the opportunity to ask pertinent questions about future commitments and offer guidance or course correction for those activities.

*In this example, it should be shared throughout the **necessary local groups** so that everyone involved in planning can have the correct information.*

Share new talent

Talent is important to pay attention to because volunteers generally only stay a short while. It is tiring to volunteer and do all that is necessary to manage your life, especially for those of us in the hemophilia community.

Identifying new talent includes:

- A new woman in our community
- A young woman who is related to our community
- A professional woman advisor
- A person who is a specialist

Following is a description of each.

*

A new woman member of our community with a newly diagnosed family member.

- Consider inviting her to events.
- Consider having a welcome person to talk with her individually and check on them to find out her needs and interests.
- A reminder that every leader needs followers so enlisting their ideas as a new person brings new light and insight into our work.

*In this example, the name and picture (if possible) of a new woman in our community should be shared throughout the **necessary local groups** so that everyone involved in planning and can have the correct information.*

A young woman who is either a family member, or a bleeder.

- Consider inviting her to activities
- See if you can find out what her interests are
- A reminder that young men have a Youth Group, but we do not have a separate group for Young Women so we need to make sure to bring them into our activities.

*In this example, the name and picture (if possible) of a new woman in our community should be shared throughout the **necessary local groups** so that everyone involved in planning and can have the correct information.*

A professional woman advisor

It is helpful to have professional women available to help us with issues and to take an interest in the work we do. They can offer new ideas, opportunities and we should include them in opportunities to speak with our group when we have workshops or planning activities. Identify areas where we need guidance and as these women are made known to us, bring their name to the Regional Council for consideration.

*In this example, the name and details about a potential professional woman advisor should be share with **Regional Coordinators and the WGHFI Chairwoman** so that everyone involved can have the correct information and especially what she likes to talk about, where her skills can be used as an advisor and her location.*

A person who is a specialist

We need help getting our work done. If you look at what we could accomplish, we have many helping hands not yet identified. The specialists at this time could be men or women and over time, they will train women in our group to take on these roles.

Photographer, writer (for reports), writer (for newspaper), spokesperson (for radio stations), speaker (for awareness activities), website support, telecommunications (to help others with Skype and Google Chat and Telecons), data collection of information by interviewing individuals, computer data analyst to create spreadsheets for reports, meeting coordinator, logistics coordinator for events, artist for posters ... and the list goes on and on.

*In this example, knowledge about specialists who may wish to volunteer to help should be shared throughout the **necessary local groups, the Regional Coordinators and the WGHFI Chairwoman** so that everyone might have an opportunity to tap into this talent and the volunteer can be appropriately placed.*

Share new idea or new opportunity

A new idea or new opportunity is not constrained in any way. It can be something as simple as a suggestion.

A common business example is: “We can save money by booking travel flights early.”

The WGHFI is a very unique element of the HFI in that we represent the women’s roles and perspectives and we are working within an established male community.

We are women with bleeding disorders, women who carry genetic issues (with or without symptoms of excessive bleeding). We are women family members of others, mostly male, who have bleeding disorders, including mothers, wives, sisters, cousins and friends.

We have something the men don’t have – a very big world-wide issue called women’s empowerment. As such, we should have our eyes wide open for opportunities in the area of women empowerment and enlist women motivational speakers and other women to join us at our meetings.

We should also be willing to look for grant and funding opportunities in areas of women empowerment to help us spawn more projects, scholarships, and travel to conferences.

We should offer ideas for workshops such as topics of interest, learning needs, icebreaker games, or favorite speakers.

New ideas and opportunities should be shared across the organization for consideration at the local, regional or national levels.

Share Future Leaders

It has been said that anyone can learn to be a manager—that anyone can take enough training classes, read the process literature, learn the computing tools and enlist help from willing workers.

But leadership comes from within—from the heart. It is not learned, it just exists and in few people. You know it when you see it. You recognize a leader as soon as you see them and hear them speak the very first time.

Be on the lookout for these people. We are creating a new women's organization that is inside an established men's organization, and with the help of young men. Some of the WGHI Leaders will be women, some will be men and others will be young men.

Identifying leaders by name must be done to ensure a new generation of individuals are being given adequate training and leadership opportunities and projects to manage. This can begin at the Chapter level where established women leaders mentor another person.

- Each Region Coordinator must have a person who is their backup who can take over as Region Coordinator at any time.
- Each Region Coordinator must have a list of new leaders in training, giving them opportunities for leadership assignments in their region over a 3 year span of time.
- Each Region Coordinator must offer an annual request for new leaders from each Chapter. From this list, selected Candidates will be given opportunities to speak and take on assignments at the Chapter level.

Sharing information about the names, talents and selection of local or regional individuals who may be candidates for future leaders will aid the overall HFI election process when new leaders need to be elected.

Share Organization and Women's Issues

Identifying issues are an important part of any organization. It helps us see problems that are blocking our progress and points to areas in need of improvement.

Organizational Issues

These issues are welcome at any time and will be logged into the WGHFI Issues log. They will be reviewed on a periodic basis by the Regional Council.

An issue should be well understood by the Regional Coordinator so that she can represent the issue if it is discussed at the Regional Council.

An organizational issue should be resolved at the appropriate level, if possible (Chapter at the Chapter level and so forth). If it needs to be escalated, it should be brought to the WG Regional Coordinator who will take it to the Regional Council.

The information to take an issue forward is best done if there is a proposal for resolution in mind.

Here is an example using an S-T-P (Situation, Target, Proposal) framework.

- Situation: We have 12 Chapter women who are at 12 different Chapters and they would like to participate in psych-social training but their Chapters don't offer sessions.
- Target: All women who wish to attend psycho-social training are given an opportunity to do so.
- Proposal: Additional funds are added to travel budget to allow women from remote chapters to travel, with an escort, to the closest Chapter for training.

Sharing the organization issues will aid in better understanding across WGHFI if this is a local issue, a regional issue or national issue.

Chapter Women's Issues

Identifying chapter women's issues are a critical part of the work we do as the WGHFI. It is likely that these issues span not just one woman in our community, but many. Understanding the issue, the reason for the issue and creating ways to address the issue are key the success of our group.

Chapter women's issues are welcome at any time and will be logged into the WGHFI Chapter Women's Issue Log. They will be anonymous in nature, not pointing to any one woman but keeping in mind good privacy practices. They will be reviewed periodically by the Regional Council to assess if they are resolved or need additional attention.

Sharing chapter women's issues will aid in a better understanding across WGHFI if this is a local issue, a regional issue or national issue.

21.2.3 Project-Directed Business Processes—Vote

The WGHFI has project-directed work. It has a beginning date (of the project) and an end date (of the project). It requires use of project management practices, as well as leadership practices.

We will use these processes to describe project-directed work:

- Identify
- Share
- **Vote**
- Fund
- Report

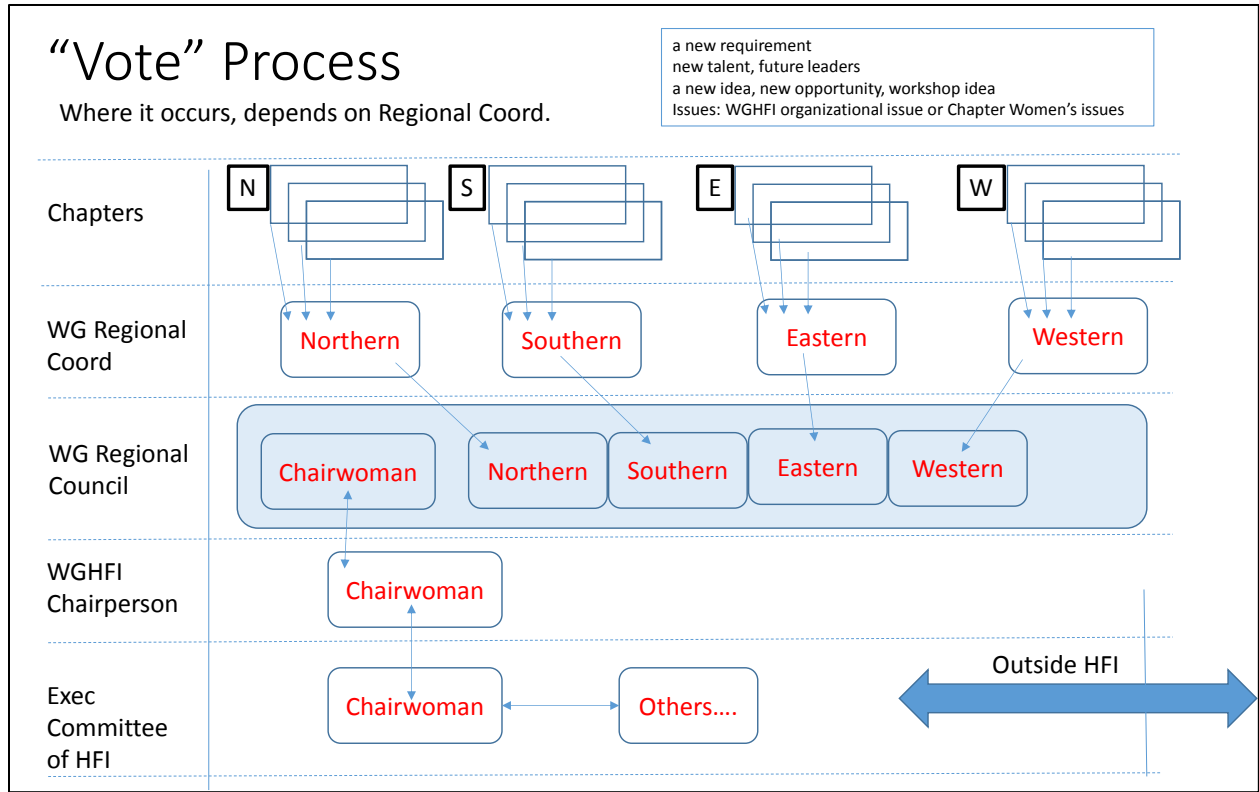
*

Vote is the third step in beginning an idea or a project. The WGHFI uses this process for the following areas:

Voting on:

- a new requirement
- new talent
- a new idea, opportunity or workshop idea
- future leaders
- an issue - organizational or chapter women's issue

Following is a description of each area.



Voting on a new requirement

Voting on a new requirement is something we must do because:

1-of an internal HFI event such as a change in operating rules, or schedule, or events.

Example: The annual HFI meeting may have more people in attendance than originally planned and we need to find dollars for additional printing of our flyers and booklets. They may also decide we need to find funding to help them support a campaign that includes mailing our booklets to other countries to spread the word of our good work.

Voting will be done by the HFI Exec Comm to find the correct placement for this new requirement. The WGHFI Chairperson is part of this committee.

2-a new source of funding exists where we might be able to receive dollars if we apply.

Example: The HFI exec committee members may find opportunities for funding new projects through grants or word of mouth with others. This may occur outside our normal annual funding cycle and there may even be a short timeframe where we are asked to develop a proposal. When we take on this opportunity we also take on the requirements to fulfill the grant requested activities and deliverables.

Voting will be done by the HFI Exec Comm to find the correct placement for this new requirement and again by the WGHFI Regional Council to ensure this group can take on this additional work and satisfy the intended grant activities. The WGHFI Chairperson is part of both of these committees.

3-an external event such as a national activity, a weather issue, or a local issue that tells us we should do things differently or at a different time.

Example: A national organization of women spread across the country may have needs at specific locations that come to our attention such as increased need for safety of our women members due to local issues and as a result we need to request male members to accompany them in transit. Also it may happen that events are cancelled due to weather or road issues.

Voting may not be able to be done due to a possible emergency situation. If possible, this new requirement should be coordinated through the WGHFI Regional Coordinator who would report this to the WGHFI Chairperson perhaps even after the fact.

4-a change in leadership who wishes us to re-think something or to accomplish different objectives.

Example: Whether it is at the chapter, region or national level, when a new leader is elected, they should have the opportunity to ask pertinent questions about future commitments and offer guidance or course correction for those activities.

The WGHFI Regional Council should assess if this is a new requirement or a change to a requirement or just a need for further information by a new leader. If it is a new requirement, voting would still need to be done at the WGHFI Regional Council.

Vote on new talent

Talent is important to pay attention to because volunteers generally only stay a short while. It is tiring to volunteer and do all that is necessary to manage your life, especially for those of us in the hemophilia community.

Voting on new talent:

- is not part of welcoming a new woman in our community
- is not part of welcoming a young woman who is related to our community
- is part of determining who will be our professional women advisors
- is part of identifying who will be named as specialists

Following is a description of each.

*

A **new woman member of our community** with a newly diagnosed family member.

- Consider inviting her to events.
- Consider having a welcome person to talk with her individually and check on them to find out her needs and interests.
- A reminder that every leader needs followers so enlisting their ideas as a new person brings new light and insight into our work.

Voting is not part of this activity.

A **young woman** who is either a family member, or a bleeder.

- Consider inviting her to activities
- See if you can find out what her interests are
- A reminder that young men have a Youth Group, but we do not have a separate group for Young Women so we need to make sure to bring them into our activities.

Voting is not part of this activity.

A **professional woman advisor**

It is helpful to have professional women available to help us with issues and to take an interest in the work we do. They can offer new ideas, opportunities and we should include them in opportunities to speak with our group when we have workshops or planning activities. Identify areas where we need guidance and as these women are made known to us, bring their name to the Regional Council for consideration.

Voting should be done by the WGHFI Regional Council to ensure this person is the right fit for our organization and if they require travel fees or honorariums that we can cover this expense.

A person who is a specialist

We need help getting our work done. If you look at what we could accomplish, we have many helping hands not yet identified. The specialists at this time could be men or women and over time, they will train women in our group to take on these roles. At the current time we do not have enough women in our community who have the skills to fill all the jobs that need to be done.

Photographer, writer (for reports), writer (for newspaper), spokesperson (for radio stations), speaker (for awareness activities), website support, telecommunications (to help others with Skype and Google Chat and Telecons), data collection of information by interviewing individuals, computer data analyst to create spreadsheets for reports, meeting coordinator, logistics coordinator for events, artist for posters ... and the list goes on and on.

A review with possible voting by the WGHFI Regional Council to ensure we don't have this role duplicated elsewhere or if this person could be used in an additional capacity.

Voting on a new idea or new opportunity

A new idea or new opportunity is not constrained in any way. It can be something as simple as a suggestion.

A common business example is: “We can save money by booking travel flights early.”

The WGHI is a very unique element of the HFI in that we represent the women’s roles and perspectives and we are working within an established male community.

We are women with bleeding disorders, women who carry genetic issues (with or without symptoms of excessive bleeding). We are women family members of others, mostly male, who have bleeding disorders, including mothers, wives, sisters, cousins and friends.

We have something the men don’t have – a very big world-wide issue called women’s empowerment. As such, we should have our eyes wide open for opportunities in the area of women empowerment and enlist women motivational speakers and other women to join us at our meetings.

We should also be willing to look for grant and funding opportunities in areas of women empowerment to help us spawn more projects, scholarships, and travel to conferences.

We should offer ideas for workshops such as topics of interest, learning needs, icebreaker games, or favorite speakers.

Voting should be done by the appropriate level of the new idea or opportunity. There may be Chapter, Regional or National voting depending on if the idea is filtered out of a big list, or if makes it to the very finals and is getting ready for approval for funding.

Voting on Future Leaders

It has been said that anyone can learn to be a manager—that anyone can take enough training classes, read the process literature, learn the computing tools and enlist help from willing workers.

But leadership comes from within—from the heart. It is not learned, it just exists and in few people. You know it when you see it. You recognize a leader as soon as you see them and hear them speak the very first time.

Be on the lookout for these people. We are creating a new women's organization that is inside an established men's organization, and with the help of young men. Some of the WGHI Leaders will be women, some will be men and others will be young men.

Voting on leaders by name must be done to ensure a new generation of individuals are being given adequate training and leadership opportunities and projects to manage. This can begin at the Chapter level where established women leaders mentor another person.

- Each Region Coordinator must have a person who is their backup who can take over as Region Coordinator at any time.
- Each Region Coordinator must have a list of new leaders in training, giving them opportunities for leadership assignments in their region over a 3 year span of time.
- Each Region Coordinator must offer an annual request for new leaders from each Chapter. From this list, selected Candidates will be given opportunities to speak and take on assignments at the Chapter level.

There are already established processes place by HFI for campaigning and voting of leaders.

Voting on Organization and Women's Issues

Voting on issues that are considered to be in scope of an organization's charter or mission are an important part of any organization's work. Voting on these issues helps us work on problems that are blocking our progress and points to areas in need of improvement.

Organizational Issues

These issues are welcome at any time and will be logged into the WGHFI Issues log. They will be reviewed on a periodic basis by the Regional Council.

An issue should be well understood by the Regional Coordinator so that she can represent the issue if it is discussed at the Regional Council.

An organizational issue should be resolved at the appropriate level, if possible (Chapter at the Chapter level and so forth). If it needs to be escalated, it should be brought to the WG Regional Coordinator who will take it to the Regional Council.

The information to take an issue forward is best done if there is a proposal for resolution in mind.

Here is an example using an S-T-P (Situation, Target, Proposal) framework.

- Situation: We have 12 Chapter women who are at 12 different Chapters and they would like to participate in psych-social training but their Chapters don't offer sessions.
- Target: All women who wish to attend psycho-social training are given an opportunity to do so.
- Proposal: Additional funds are added to travel budget to allow women from remote chapters to travel, with an escort, to the closest Chapter for training.

Voting should be done by the appropriate level of the issue. There may be Chapter, Regional or National voting depending on if the proposal to resolve the issue is filtered out of a big list, or if makes it to the very finals and is getting ready for approval for funding.

Chapter Women's Issues

Identifying chapter women's issues are a critical part of the work we do as the WGHI. It is likely that these issues span not just one woman in our community, but many. Understanding the issue, the reason for the issue and creating ways to address the issue are key the success of our group.

Chapter women's issues are welcome at any time and will be logged into the WGHI Chapter Women's Issue Log. They will be anonymous in nature, not pointing to any one woman but keeping in mind good privacy practices. They will be reviewed periodically by the Regional Council to assess if they are resolved or need additional attention.

Voting should be done by the appropriate level of the issue. There may be Chapter, Regional or National voting depending on if the proposal to resolve the issue is filtered out of a big list, or if makes it to the very finals and is getting ready for approval for funding.

21.2.4 Project-Directed Business Processes—Fund

Most ideas turn into projects which create a need for funds. As simple as an awareness activity in a park setting, it may create a need to refund individuals for transportation, a printer for posters and a permit for a booth during a fair.

The WGHFI has project-directed work. All projects have a beginning date (of the project) and an end date (of the project). It requires use of project management practices, manage practices, as well as leadership practices.

We will use these processes to describe project-directed work:

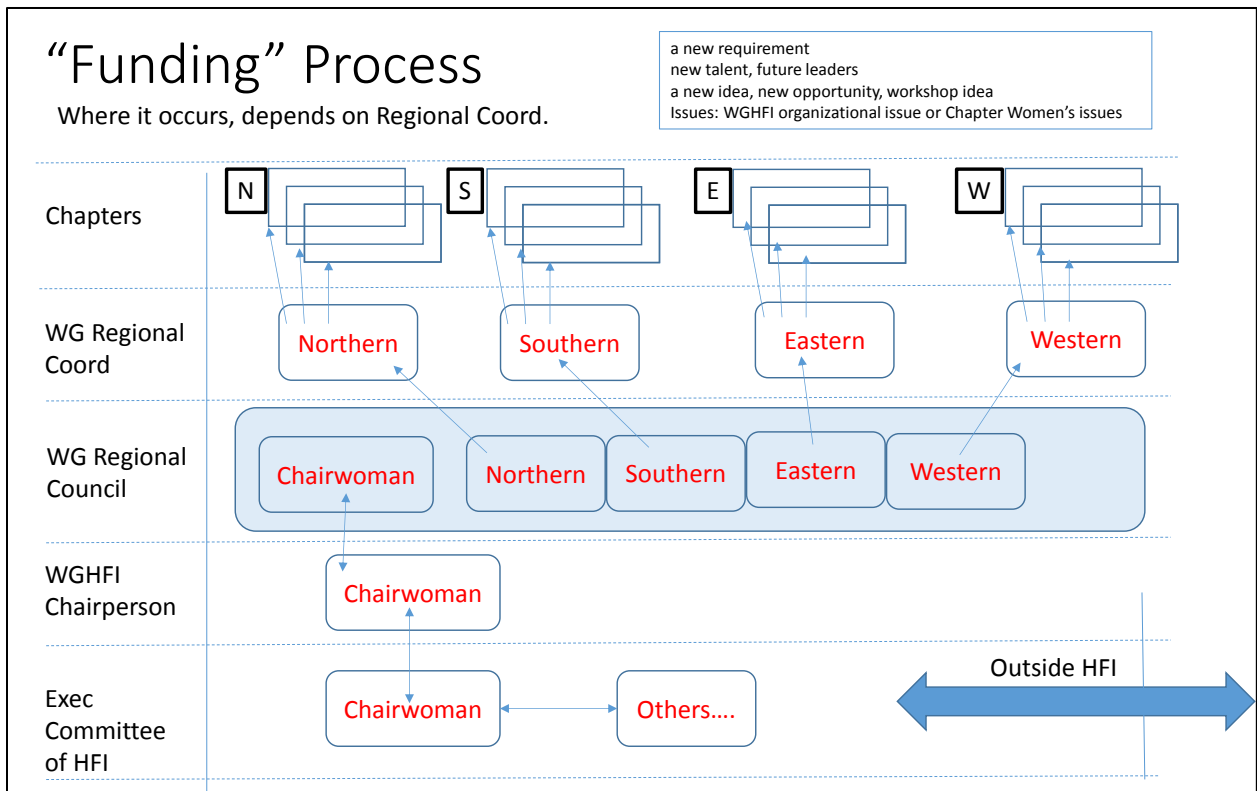
- Identify
- Share
- Vote
- **Fund**
- Report

*

Funding is the fourth step in beginning an idea or a project. The WGHFI uses this process for the following areas:

Funding:

- a new requirement
- new talent
- a new idea, opportunity or workshop idea
- future leaders
- an issue – organizational or Chapter women’s issue



Funding a new requirement

A new requirement is something we must do because:

1-of an internal HFI event such as a change in operating rules, or schedule, or events.

Example: The annual HFI meeting may have more people in attendance than originally planned and we need to find dollars for additional printing of our flyers and booklets. They may also decide we need to find funding to help them support a campaign that includes mailing our booklets to other countries to spread the word of our good work.

The funding for this new requirement would need to be discussed at the Exec Comm of HFI meeting with the WGHFI Chairperson. If the WGHFI needs to absorb this new requirement in their budget, it is possible it may delay the work of another project.

2-a new source of funding exists where we might be able to receive dollars if we apply.

Example: The HFI exec committee members may find opportunities for funding new projects through grants or word of mouth with others. This may occur outside our normal annual funding cycle and there may even be a short timeframe where we are

asked to develop a proposal. When we take on this opportunity we also take on the requirements to fulfill the grant requested activities and deliverables.

The funding for this new opportunity would need to be discussed at the Exec Comm of HFI meeting with the WGHI Chairperson. If the new opportunity is a grant from a charitable organization and a proposal needs to be developed, the details of the proposal requirements, the project requirements, including all deliverables and activities must be reviewed with WGHI Chairperson and WGHI Regional Council to ensure it can be carried out before the funding is approved.

3-an external event such as a national activity, a weather issue, or a local issue that tells us we should do things differently or at a different time.

Example: A national organization of women spread across the country may have needs at specific locations that come to our attention such as increased need for safety of our women members due to local issues and as a result we need to request male members to accompany them in transit. Also it may happen that events are cancelled due to weather or road issues.

The funding for this activity, if cancelled, would need to be assessed by the Exec Comm of the HFI where the WGHI Chairperson is a member.

4-a change in leadership who wishes us to re-think something or to accomplish different objectives.

Example: Whether it is at the chapter, region or national level, when a new leader is elected, they should have the opportunity to ask pertinent questions about future commitments and offer guidance or course correction for those activities.

The funding for this activity, if changed may or may not need to be assessed by the Exec Comm of the HFI where the WGHI Chairperson is a member but would definitely need to be reviewed by the WGHI Regional Council.

Funding new talent

Talent is important to pay attention to because volunteers generally only stay a short while. It is tiring to volunteer and do all that is necessary to manage your life, especially for those of us in the hemophilia community.

Identifying new talent includes:

- A new woman in our community
- A young woman who is related to our community
- A professional woman advisor
- A person who is a specialist

Following is a description of each.

*

A **new woman member of our community** with a newly diagnosed family member.

- Consider inviting her to events.
- Consider having a welcome person to talk with her individually and check on them to find out her needs and interests.
- A reminder that every leader needs followers so enlisting their ideas as a new person brings new light and insight into our work.

Funding a welcome kit for a new woman in our community would be done by the Regional Women's Group budget. It may include transportation allowance to attend activities, a family visit to the hemophilia treatment center or for a psycho-social visit.

A **young woman** who is either a family member, or a bleeder.

- Consider inviting her to activities
- See if you can find out what her interests are
- A reminder that young men have a Youth Group, but we do not have a separate group for Young Women so we need to make sure to bring them into our activities.

Funding a welcome kit for a new woman in our community would be done by the Regional Women's Group budget. It may include transportation allowance to attend activities, a family visit to the hemophilia treatment center or for a psycho-social visit.

A professional woman advisor

It is helpful to have professional women available to help us with issues and to take an interest in the work we do. They can offer new ideas, opportunities and we should include them in opportunities to speak with our group when we have workshops or planning activities. Identify areas where we need guidance and as these women are made known to us, bring their name to the Regional Council for consideration.

Funding for an advisor may include transportation costs for her to participate in a workshop. She may also require an honorarium for her presentation.

A person who is a specialist

We need help getting our work done. If you look at what we could accomplish, we have many helping hands not yet identified. The specialists at this time could be men or women and over time, they will train women in our group to take on these roles.

Photographer, writer (for reports), writer (for newspaper), spokesperson (for radio stations), speaker (for awareness activities), website support, telecommunications (to help others with Skype and Google Chat and Telecons), data collection of information by interviewing individuals, computer data analyst to create spreadsheets for reports, meeting coordinator, logistics coordinator for events, artist for posters ... and the list goes on and on.

Funding for a specialist will vary. Some may require no funding at all and others could require funding for specific aspects of their work. A photographer may be a willing person to take pictures but not have a camera and would need to borrow one from someone. A telecommunications specialist may have the technical savvy to coordinate meetings but may need reimbursement for their telephone fees. A logistics coordinator may be happy to help set up an event but would need fees to pay for permits or registration or banners – most likely ahead of the event. This type of funding needs to be carefully planned in the project and not left for the last minute.

Funding new idea or new opportunity

A new idea or new opportunity is not constrained in any way. It can be something as simple as a suggestion.

A common business example is: “We can save money by booking travel flights early.”

The WGHFI is a very unique element of the HFI in that we represent the women’s roles and perspectives and we are working within an established male community.

We are women with bleeding disorders, women who carry genetic issues (with or without symptoms of excessive bleeding). We are women family members of others, mostly male, who have bleeding disorders, including mothers, wives, sisters, cousins and friends.

We have something the men don’t have – a very big world-wide issue called women’s empowerment. As such, we should have our eyes wide open for opportunities in the area of women empowerment and enlist women motivational speakers and other women to join us at our meetings.

We should also be willing to look for grant and funding opportunities in areas of women empowerment to help us spawn more projects, scholarships, and travel to conferences.

We should offer ideas for workshops such as topics of interest, learning needs, icebreaker games, or favorite speakers.

Funding new ideas usually don’t happen right off—they require estimates and approvals. Included with the project proposal should be an estimate for funding needs and timeframe.

Funding from a new opportunity—a grant—may occur at the beginning of a project and may be given to the organization based on deliverables that are considered complete.

Funding for travel to conferences should be done at the beginning of the calendar year and set aside to be allocated 90 days in advance of the conference or travel activity.

Funding Future Leaders

It has been said that anyone can learn to be a manager—that anyone can take enough training classes, read the process literature, learn the computing tools and enlist help from willing workers.

But leadership comes from within—from the heart. It is not learned, it just exists and in few people. You know it when you see it. You recognize a leader as soon as you see them and hear them speak the very first time.

Be on the lookout for these people. We are creating a new women's organization that is inside an established men's organization, and with the help of young men. Some of the WGHI Leaders will be women, some will be men and others will be young men.

Identifying leaders by name must be done to ensure a new generation of individuals are being given adequate training and leadership opportunities and projects to manage. This can begin at the Chapter level where established women leaders mentor another person.

- Each Region Coordinator must have a person who is their backup who can take over as Region Coordinator at any time.
- Each Region Coordinator must have a list of new leaders in training, giving them opportunities for leadership assignments in their region over a 3 year span of time.
- Each Region Coordinator must offer an annual request for new leaders from each Chapter. From this list, selected Candidates will be given opportunities to speak and take on assignments at the Chapter level.

Funding for leadership opportunities may cost nothing or may cost in the form of transportation or travel to conferences. This should be done at the beginning of the calendar year and set aside to be allocated 90 days in advance of the conference or travel activity.

Funding Organization and Women's Issues

Funding activities to solve issues are an important part of any organization. It helps us improve or remedy problems that are blocking our progress and points to areas in need of improvement.

Organizational Issues

These issues are welcome at any time and will be logged into the WGHFI Issues log. They will be reviewed on a periodic basis by the Regional Council.

An issue should be well understood by the Regional Coordinator so that she can represent the issue if it is discussed at the Regional Council.

An organizational issue should be resolved at the appropriate level, if possible (Chapter at the Chapter level and so forth). If it needs to be escalated, it should be brought to the WG Regional Coordinator who will take it to the Regional Council.

The information to take an issue forward is best done if there is a proposal for resolution in mind.

Here is an example using an S-T-P (Situation, Target, Proposal) framework.

- Situation: We have 12 Chapter women who are at 12 different Chapters and they would like to participate in psych-social training but their Chapters don't offer sessions.
- Target: All women who wish to attend psycho-social training are given an opportunity to do so.
- Proposal: Additional funds are added to travel budget to allow women from remote chapters to travel, with an escort, to the closest Chapter for training.

Funding for organization issues will vary depending on the proposal. In the case above, funding for travel would be approved through the appropriate level.

Chapter Women's Issues

Identifying chapter women's issues are a critical part of the work we do as the WGHFI. It is likely that these issues span not just one woman in our community, but many. Understanding the issue, the reason for the issue and creating ways to address the issue are key the success of our group.

Chapter women's issues are welcome at any time and will be logged into the WGHFI Chapter Women's Issue Log. They will be anonymous in nature, not pointing to any one woman but keeping in mind good privacy practices. They will be reviewed periodically by the Regional Council to assess if they are resolved or need additional attention.

The information to take an issue forward is best done if there is a proposal for resolution in mind.

Here is an example using an S-T-P (Situation, Target, Proposal) framework.

- Situation: We have 17 Chapter women who are at 6 remote Chapters. They indicate they may have infections, and are in need women's medical health check-ups.
- Target: All women who indicate they may have infections, and are in need medical health check-ups are given a travel allowance and escort to accomplish this. Their doctor bill and tests are paid for as well.
- Proposal: Additional funds are added to WGHI to allow women from remote chapters to travel, with an escort, to the closest clinic for testing and medical check-ups.

Funding for Chapter women's medical, employment and social issues will vary depending on the proposal. In the case above, funding for travel and medical expenses would be approved through the appropriate level.

21.2.5 Project-Directed Business Processes—Report

The WGHFI has project-directed work. It has a beginning date (of the project) and an end date (of the project). It requires use of project management practices, as well as leadership practices.

Reporting is an essential part of our work as we must provide awareness of our activities within our organization and outside of our organization. Charitable organizations that fund our activities expect to know what we are doing and how we are accomplish the work that they are funding. To improve the work that we do, it's helpful to see what others are doing and then apply their best practices to other areas within the organization. Reporting also shows us where we have gaps in completing our work, issues that need to be addressed and areas where we simply need help.

We will use these processes to describe project-directed work:

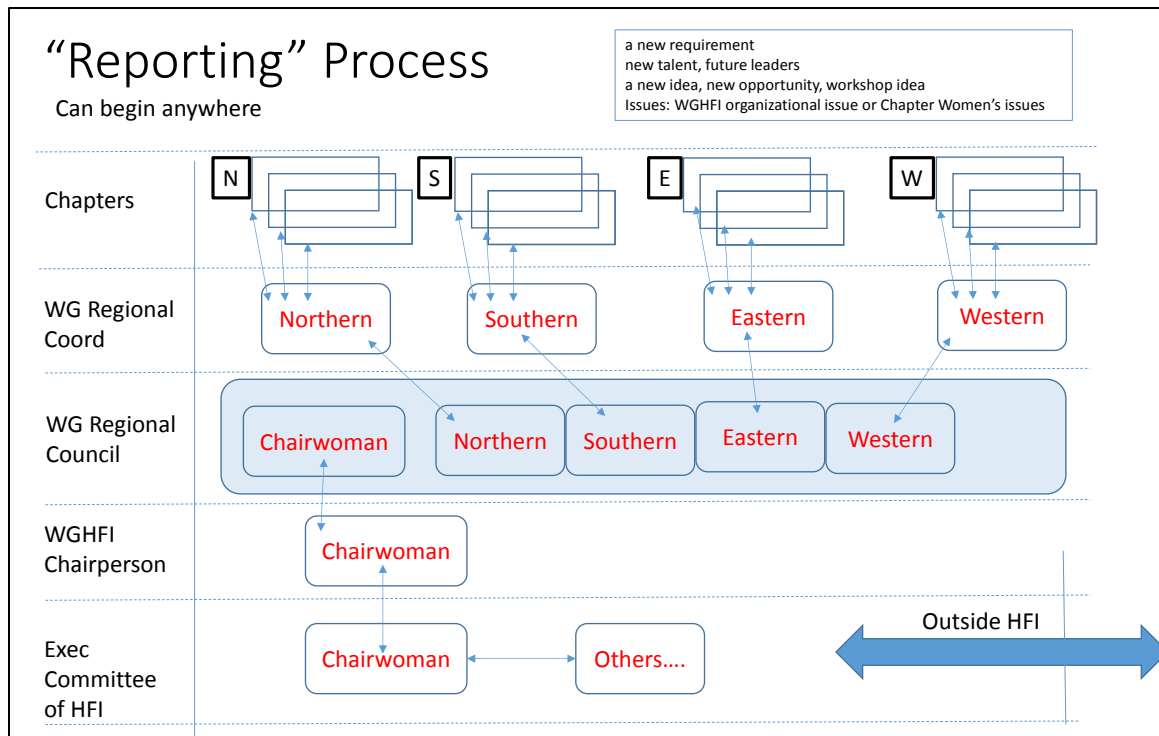
- Identify
- Share
- Vote
- Fund
- **Report**

Reporting is the last step in our process even though it occurs throughout the lifecycle of a project as well as at the completion a project. The WGHFI uses the reporting process for the following areas:

Reporting:

- The incorporation of a new requirement into our work activities
- The discovery or information about new talent
- Information about a new idea, new opportunity or a workshop idea
- The activities of our future leaders
- Information about issues -organizational issue or Chapter Women's issues

Following is a description of each area.



Reporting a new requirement

Reporting a new requirement that falls in the scope of our work activities is something we must do because:

1-of an internal HFI event such as a change in operating rules, or schedule, or events.

Example: The annual HFI meeting may have more people in attendance than originally planned and we need to find dollars for additional printing of our flyers and booklets. They may also decide we need to find funding to help them support a campaign that includes mailing our booklets to other countries to spread the word of our good work.

Reporting this will bring awareness to ensure the new requirement and related information are incorporated into the proper project plans, schedules, status reports, estimating and expense spreadsheets (and other project deliverables).

2-a new source of funding exists where we might be able to receive dollars if we apply.

Example: The HFI exec committee members may find opportunities for funding new projects through grants or word of mouth with others. This may occur outside our

normal annual funding cycle and there may even be a short timeframe where we are asked to develop a proposal. When we take on this opportunity we also take on the requirements to fulfill the grant requested activities and deliverables.

Reporting new funding opportunities will help others learn about these new opportunities and ideas where they may wish to create proposals for future projects. Reporting this is part of transparency which is required for trust within the organization so that everyone can compete for new opportunities, if they wish.

3-an external event such as a national activity, a weather issue, or a local issue that tells us we should do things differently or at a different time.

Example: A national organization of women spread across the country may have needs at specific locations that come to our attention such as increased need for safety of our women members due to local issues and as a result we need to request male members to accompany them in transit. Also it may happen that events are cancelled due to weather or road issues.

Reporting this will help others learn about how to handle emergencies and to understand where unexpected situations may exist for future project planning.

4-a change in leadership who wishes us to re-think something or to accomplish different objectives.

Example: Whether it is at the chapter, region or national level, when a new leader is elected, they should have the opportunity to ask pertinent questions about future commitments and offer guidance or course correction for those activities.

Reporting this will help others learn about the thoughts of their new leaders and how they may wish to change their communication with them to handle new questions, issues or change in business practices.

Reporting on new talent

Talent is important to pay attention to because volunteers generally only stay a short while. It is tiring to volunteer and do all that is necessary to manage your life, especially for those of us in the hemophilia community.

Reporting information about new talent includes:

- Learning more about a new woman in our community
- Becoming more connected with a young woman who is related to our community
- Thanking a professional woman advisor
- Giving appreciation to a person who is a specialist

*

A **new woman member of our community** with a newly diagnosed family member.

- Consider inviting her to events.
- Consider having a welcome person to talk with her individually and check on them to find out her needs and interests.
- A reminder that every leader needs followers so enlisting their ideas as a new person brings new light and insight into our work.

Reporting this will allow others to welcome her when the opportunity arises. It should also be of interest to those who are maintaining the patient registry for that chapter.

A **young woman** who is either a family member, or a bleeder.

- Consider inviting her to activities
- See if you can find out what her interests are
- A reminder that young men have a Youth Group, but we do not have a separate group for Young Women so we need to make sure to bring them into our activities.

Reporting this will allow others to welcome her when the opportunity arises. It should also be of interest to those who are maintaining the patient registry for that chapter.

A professional woman advisor

It is helpful to have professional women available to help us with issues and to take an interest in the work we do. They can offer new ideas, opportunities and we should include them in opportunities to speak with our group when we have workshops or planning activities. Identify areas where we need guidance and as these women are made known to us, bring their name to the Regional Council for consideration.

Reporting this will remind us that there is help within the professional community for our work. Publishing thank you's to advisors and speakers through our activity reports and posting photos online provide gracious feedback for their kindness in working with us, and may encourage others to offer their help as well.

A person who is a specialist

We need help getting our work done. If you look at what we could accomplish, we have many helping hands not yet identified. The specialists at this time could be men or women and over time, they will train women in our group to take on these roles.

Photographer, writer (for reports), writer (for newspaper), spokesperson (for radio stations), speaker (for awareness activities), website support, telecommunications (to help others with Skype and Google Chat and Telecons), data collection of information by interviewing individuals, computer data analyst to create spreadsheets for reports, meeting coordinator, logistics coordinator for events, artist for posters ... and the list goes on and on.

Reporting this will remind us that there is help within the specialist community for our work. Publishing thank you's to our specialists through our activity reports and posting photos online provide gracious feedback for their kindness in working with us, and may encourage others to offer their help as well..

Reporting a new idea or new opportunity

A new idea or new opportunity is not constrained in any way. It can be something as simple as a suggestion.

A common business example is: “We can save money by booking travel flights early.”

The WGHFI is a very unique element of the HFI in that we represent the women’s roles and perspectives and we are working within an established male community.

We are women with bleeding disorders, women who carry genetic issues (with or without symptoms of excessive bleeding). We are women family members of others, mostly male, who have bleeding disorders, including mothers, wives, sisters, cousins and friends.

We have something the men don’t have – a very big world-wide issue called women’s empowerment. As such, we should have our eyes wide open for opportunities in the area of women empowerment and enlist women motivational speakers and other women to join us at our meetings.

We should also be willing to look for grant and funding opportunities in areas of women empowerment to help us spawn more projects, scholarships, and travel to conferences.

We should offer ideas for workshops such as topics of interest, learning needs, icebreaker games, or favorite speakers.

Reporting new ideas or opportunities are part of transparency and building trust. They can be sent through emails or as part of an ongoing WGHFI log where we keep these gems. Over time they will include scholarship opportunities, job opportunities, and other lists that will evolve as this organization finds it’s niche to help women in our community.

Reporting on our Future Leaders

It has been said that anyone can learn to be a manager – that anyone can take enough training classes, read the process literature, learn the computing tools and enlist help from willing workers.

But leadership comes from within – from the heart. It is not learned, it just exists and in few people. You know it when you see it. You recognize a leader as soon as you see them and hear them speak the very first time.

Be on the lookout for these people. We are creating a new women’s organization that is inside an established men’s organization, and with the help of young men. Some of the WGHFI Leaders will be women, some will be men and others will be young men.

Including leaders by name in reports must be done to ensure a new generation of individuals are being given adequate training and leadership opportunities and projects to manage. This can begin at the Chapter level where established women leaders mentor another person.

- Each Region Coordinator must have a person who is their backup who can take over as Region Coordinator at any time.
- Each Region Coordinator must have a list of new leaders in training, giving them opportunities for leadership assignments in their region over a 3 year span of time.
- Each Region Coordinator must offer an annual request for new leaders from each Chapter. From this list, selected Candidates will be given opportunities to speak and take on assignments at the Chapter level.

Reporting on activities or good things our future leaders are doing is part of awareness of good people doing good work. Taking pictures and including them in reports, or on facebook is a great way to report what our future leaders are doing to help and will give others ideas as to what they could also be doing.

Report Organization and Women’s Issues

Reporting issues are an important part of any organization. It helps us see problems that are blocking our progress and points to areas in need of improvement.

Organizational Issues

These issues are welcome at any time and will be logged into the WGHFI Issues log. They will be reviewed on a periodic basis by the Regional Council.

An issue should be well understood by the Regional Coordinator so that she can represent the issue if it is discussed at the Regional Council.

An organizational issue should be resolved at the appropriate level, if possible (Chapter at the Chapter level and so forth). If it needs to be escalated, it should be brought to the WG Regional Coordinator who will take it to the Regional Council.

The information to take an issue forward is best done if there is a proposal for resolution in mind.

Here is an example using an S-T-P (Situation, Target, Proposal) framework.

- Situation: We have 12 Chapter women who are at 12 different Chapters and they would like to participate in psych-social training but their Chapters don't offer sessions.
- Target: All women who wish to attend psycho-social training are given an opportunity to do so.
- Proposal: Additional funds are added to travel budget to allow women from remote chapters to travel, with an escort, to the closest Chapter for training.

Reporting issues requires that WGHFI have a documented list of issues with details about each issue to ensure follow up and resolution and they review this list periodically to assess progress.

Chapter Women's Issues

Reporting chapter women's issues are a critical part of the work we do as the WGHFI. It is likely that these issues span not just one woman in our community, but many. Understanding the issue, the reason for the issue and creating ways to address the issue are key the success of our group.

Chapter women's issues are welcome at any time and will be logged into the WGHFI Chapter Women's Issue Log. They will be anonymous in nature, not pointing to any one woman but keeping in mind good privacy practices. They will be reviewed periodically by the Regional Council to assess if they are resolved or need additional attention.

Reporting chapter women's issues requires that WGHFI have a documented list of these issues with details about each issue to ensure follow up and resolution and they review this list periodically to assess progress. Due to personal nature of some of these items, personal information cannot be associated with these issues.

22. Glossary

Bleeding Disorders—A general term for a wide range of medical conditions that result in poor blood clotting and prolonged or excessive bleeding. These disorders can be a result of platelet defects or deficiencies of clotting proteins known as “clotting factors”. Bleeding disorders may be acquired or due to other conditions. Examples of congenital bleeding disorders are hemophilia A or B (factor VIII deficiency or factor IX deficiency, respectively), von Willebrand Disease, or rare deficiency or other clotting factors such as factor V.

Clotting Factors—These are proteins in the blood plasma that are essential to the blood-clotting process. Clotting factor concentrates come as freeze-dried powders that are reconstituted with sterile water or saline, and the solution is infused into a vein to treat a bleed. Concentrates of factor VII, VIII, IX, fibrinogen and von Willebrand factor are available. There is currently no clotting factor concentrate available to treat factor V deficiency.

Congenital disorder—A disease or disorder that results from genetic abnormalities. A person with a congenital disorder is born with the disorder.

CwH—Child with hemophilia.

Diagnosis—(as for bleeding disorders): Requires a set of blood tests, including a complete blood count (CBC) with a platelet count and a prothrombin time (PT) and an activated partial thromboplastin time (APTT) to screen for factor deficiencies. Specific testing for factors VIII, IX or other clotting factor activities and von Willebrand factor are important and often require having samples run by reference coagulation laboratories.

Factor products—Clotting factors, or factor concentrates, are the main treatment for or prevention of bleeding due to hemophilia. Factor products replace the clotting factor that is too low or missing from the blood and are dosed according to patient weight, the severity of bleeding, or the anticipated need for prophylaxis.

Hemophilia—A rare bleeding disorder, usually inherited. In a person with hemophilia, the blood clotting is delayed. A person with hemophilia may bleed longer than others after an injury and may also bleed internally or even spontaneously. Continued bleeding can damage organs or tissues and joints, and it may be fatal; delayed clotting also leads to poor wound healing. Hemophilia is classified as mild, moderate or severe. In mild hemophilia, greater than 5 percent to 40 percent of a specific clotting factor activity is present and it is characterized by infrequent bleeding, sometimes only after only major injuries or surgery. In moderately severe hemophilia, only 1 percent to 5 percent of specific clotting factor activity remains, and is characterized by excessive bleeding after injury. In severe hemophilia, less than 1 percent of a specific clotting factor activity or an undetectable amount by current assays is found, and it is characterized by more frequent and spontaneous bleeding episodes.

Signs and symptoms (of bleeding)—A sign is visible evidence of a disease. A symptom is not visible, but it is felt by the person with the disease. An external cut where bleeding is prolonged

is a sign of a bleed. A symptom of a joint bleed in a person with hemophilia may be pain or tingling in the joint. A person with a bleeding disorder who visits an emergency room may experience delayed care because there are often no signs of an internal bleeding episode.

NGO—A non-governmental organization (NGO) is an organization that is neither a part of a government nor a conventional for-profit business. Usually set up by ordinary citizens, NGOs may be funded by governments, foundations or businesses. Some avoid formal funding altogether and are run primarily by volunteers. NGOs are highly diverse groups of organizations engaged in a wide range of activities, and take different forms in different parts of the world.

PwH—Person with hemophilia.



23. References

Here are some links:

<http://www.stepsforliving.hemophilia.org/resources/next-step-resources> -

<http://www.stepsforliving.hemophilia.org/step-out/non-factor-treatment/pain-management>

<http://www.stepsforliving.hemophilia.org/basics-of-bleeding-disorders>

www.hemaware.org (google search for topics)

<http://www.stepsforliving.hemophilia.org/>

<http://www.stepsforliving.hemophilia.org/first-step/maintaining-a-healthy-body/physical-activity>

www.victoryforwomen.org

<http://www.hemophilia.ca/en/>

<http://www.caregiver.com/>

<http://www.hemophiliabangalore.org/faq.html>

<http://www.aboveandbeyondhemophilia.net/en/hemophilia-health/sexual-health/answers-to-common-questions-about-hemophilia-and-sex/>

<http://www.aboveandbeyondhemophilia.net/en/hemophilia-health/sexual-health/sexual-function-and-dysfunction-in-hemophilia/>

Special thanks to these contributing authors and reviewers

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2013-2014

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Women's Group Hemophilia Federation (India)

WOMEN'S LEADERSHIP GUIDE

