

# YOUNG VOICES



**WFH**

WORLD FEDERATION OF HEMOPHILIA

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**World Federation of Hemophilia**

1425 René Lévesque Boulevard West, Suite 1010  
Montréal, Québec H3G 1T7  
CANADA

Tel.: (514) 875-7944

Fax: (514) 875-8916

E-mail: [wfh@wfh.org](mailto:wfh@wfh.org)

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**YOUNG  
VOICES**



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# Introduction

The strength of the World Federation of Hemophilia (WFH) and of its national member organizations lies in the commitment of inspiring leaders who work every day to advance the common vision of Treatment for All. However, many patient organizations struggle to engage young people within their communities and there is a need to inspire more active participation from them.

*Young Voices* is a series of articles designed for young people interested in exploring involvement in the inherited bleeding disorders community, especially in participating in or even initiating a youth group. Originally these articles were periodically published online at [www.wfh.org](http://www.wfh.org) over the past two years. We have now gathered the articles into a single resource to help identify, mobilize, and empower future leaders to participate in the global conversation and effect positive change in their communities. In addition, videos of two young people presenting the inspiring successes of their youth groups are also available at [www.wfh.org](http://www.wfh.org).

As you read the *Young Voices* articles, consider sharing them with other young people in your community. At the end of each article you will find *Show of Hands* and *Digging Deeper* suggestions for starting conversations with your peers about each topic. The best way to ensure the success of your youth group is to engage other young people in a team approach to shared values, visions, and goals with open and clear communication. Together, you can carry out exciting projects to achieve the objectives you identify as important to your youth group.

There are many keys to a successful youth group and they are all connected to one another. In each *Young Voices* article you will find connections to other *Young Voices* articles that develop related themes. You can read this series in the order in which they were originally published or follow the connections from one article to another as you explore the theme that most interests you.

The *Young Voices* series is just a starting point and we hope that you will enjoy reading and discussing them within your community. Let us know if you find them useful, share your successes with us, and tell us about the resources that would help you overcome the challenges facing your youth group by emailing [publications@wfh.org](mailto:publications@wfh.org).

We look forward to hearing from you!

# Leadership in the bleeding disorders community

Steve Jobs, Indira Gandhi, an inspirational member of your hemophilia organization... Most people can name a great leader, but what qualities do they share and how can you go about becoming one?

Leadership is a process of social interaction and influence, which motivates and maximizes the efforts of others towards a common goal.

## WHAT MAKES A GOOD LEADER?

### *Followers*

Although great leaders share some key characteristics, it is not personality alone that determines whether a leader is successful or not. Followers count too! Without people willing to support and carry out your ideas, you are an individual trying to make a difference, as opposed to the leader of an organization whose members are working towards a shared objective.

You need to know your team well in order to be an effective leader. Imagine a team member agrees to work on a project but keeps turning up late to work. You are worried about her ability to complete the task. Rather than confronting her aggressively a week before the deadline, it would be more productive to ask if something is affecting her work (many things can impact ability to work or concentrate on a project - a new treatment schedule, school or work commitments, personal situation etc.), and offer help if needed.

In order to attract followers, you need to inspire confidence, be a motivator, and be attentive to your team's needs.

### *Know yourself*

Truly knowing your own strengths and limitations enables you to leverage the former and work on overcoming the latter. Furthermore, it can lead to a deeper understanding of yourself. Just as you need to know what drives team members, you must have an honest understanding of your own knowledge, abilities, and desires, especially as this can bolster your sense of direction and self-confidence.

For more on **communication**, check out the article on page 24

### *Communication and empathy*

Communication is a two-way street, and a lot of it is non-verbal. You are an example to others through your words and your actions. This not only includes how you treat others but how you treat yourself - remember to try and be the kind of person you would look up to.

Good leaders practice the art of attentive listening and are empathetic. This isn't just about looking at someone when they speak to you. An attentive listener picks up on and acknowledges the emotional cues that the individual (or group) give while speaking.

# QUALITIES OF A GOOD LEADER



## KNOW YOURSELF

BUILD  
ON YOUR  
STRENGTHS



OVERCOME  
YOUR WEAKNESSES



## COMMUNICATION IS CRITICAL

- BE CLEAR. GET YOUR MESSAGE ACROSS.
- LISTEN TO THE NEEDS OF OTHERS.



## BE EMPATHETIC

### LISTEN & UNDERSTAND

The point of view and experience of others provides better insight on how to be the leader they need.



## BE ADAPTABLE

**EVERY SITUATION CALLS  
FOR A DIFFERENT KIND OF LEADERSHIP**  
A good leader can read situations and adapt.

## BE AN EXAMPLE



Be the kind of person  
you would look up to.



Imagine a friend is having problems with his family; he wants to join a sports team but his parents are worried about the possibility of increased bleeds. Listen to what he has to say – that means no texting while talking! Identify the emotions he expresses, and, once he has stopped speaking, use your own words to describe how he feels about the situation. For example: “It sounds like you feel frustrated and disempowered that your parents don’t support your desire to play more team sports.” Sometimes this is all people want – try not to offer solutions unless the person asks for advice.

### **Adaptability**

Every situation calls for a different kind of leadership; there is no one size fits all methodology. A good leader is able to determine the type of action a specific situation requires.

For example, a person who has just found out that he has a bleeding disorder and is still coming to terms with the diagnosis will need to be approached and engaged in a different way than a person who has lived with the diagnosis for longer.

For more on **values**, check out the article on page 6

### **LEADERSHIP IN THE BLEEDING DISORDERS COMMUNITY**

The bleeding disorders community has a unique identity but like any other group, it needs cohesion, as well as a unified direction that reflects the values of its members. Understanding followers’ needs and motivations is therefore very important for the community’s leaders.

Good leaders encourage team members to contribute their ideas and be involved in all aspects of an organization or project. This demonstrates confidence in their abilities, interest in their opinions, and fosters deeper commitment, more open communication, and improved productivity.

## **SHOW OF HANDS**

### **USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT LEADERSHIP**

Ask your youth group which of these qualities is most important in a leader. Invite them to explain their choice(s).

- A** Inspiring and motivating followers
- B** Being a good communicator
- C** Knowing yourself
- D** Being empathetic
- E** Adaptability

## **DIGGING DEEPER**

### **INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE**

Present the ideas in this article to your youth group, or invite them each to read it, and ask them who they think is a good leader in your community. What can the leaders of your youth group learn from these examples?

In addition to guiding the community, as a leader you are a role model and motivator for people living with bleeding disorders. Although people with a medical condition face certain challenges, you can demonstrate and support the happy, successful life that people with bleeding disorders can have and should be striving for.

*Originally published online November 2013*

## **WHAT'S NEXT?**

Do you want to make a change in the lives of people with bleeding disorders? Maybe you want to create or join a network for young people with bleeding disorders, or perhaps you have a great idea for a fundraising event. A youth group is a great way to meet others who have similar goals and face similar challenges. Find out more about starting a youth group, or what to expect when you join one, in the next **Young Voices** article.

# Fun, friendly, life-changing: Youth groups

A youth group is much more than a collection of young people who meet on a regular basis. In addition to helping young people gain self-confidence, improve interpersonal and communication skills, and develop a strong support network, a youth group is a place where you can celebrate being part of the bleeding disorders community. You can share the challenges and joys of living with a rare condition, find new friends, get advice, participate in fun and educational activities, and take steps to make a change in your community.

## STARTING A YOUTH GROUP

Your national or local hemophilia society might already have a youth chapter. If not, they may be able to put you in touch with other young people interested in forming a youth committee and suggest specific ways for you to get involved.

Your group will need to be based somewhere, and although meetings could start out in somebody's house, it makes sense to find a larger space. See if your school, local hemophilia chapter, library, community centre, or religious organization has space that you can use. It should be accessible to all members (look for ground level rooms or buildings with elevators and access ramps instead of stairs).

## MEMBERS

Of course you can't have a youth group without members!

Age may be more about how you feel than calendar years, but a youth group is for young people. You can decide the appropriate range for your group, but the World Federation of Hemophilia (WFH) defines young people as those between the ages of 15 and 30.

For more on **member retention**, check out the article on page 21

Good places to recruit members include your local hemophilia centre and the hematology unit of nearby hospitals or clinics. An eye-catching poster with contact and meeting information, or a pamphlet that people can keep, are good ways to promote your group. You could create a Facebook group or other online social media presence, though this may be more beneficial once you have a solid member base. Word of mouth is always a great way to let people know about your group, so talk it up!

## VALUES, VISIONS, AND GOALS

Values, vision, and goals help solidify the reasons for your group's existence, what you are working towards, and what members can expect from their involvement.

**Values** are qualities that are considered worthwhile, such as choosing to be compassionate rather than indifferent about other peoples' illnesses. Values represent the group's highest priorities and are a deep source of motivation, providing structure and guidance for decision making.

Group values are shared by members and could include:

- Inclusivity – we all have a bleeding disorder and are therefore part of a vibrant community
- Commonalities over differences – no matter what race, religion, customs, or practices we may have, we are united by the fact that we are all living with a bleeding disorder
- Facing the realities of life with a bleeding disorder while standing proud and fighting for improvements

For more on **values, vision, and goals**, check out the article on page 18

**Vision** is about the future – what your group wants to be or the kind of world it would like to be part of. An organization’s vision is inspiring and provides direction. For example, the WFH’s vision is “Treatment For All”: that one day, all people with a bleeding disorder will have proper care, no matter where they live.

Your group’s vision could include:

- Local sports teams welcoming teens with bleeding disorders
- Affordable access to treatment for all young people with bleeding disorders in your country
- A community of friends and family that understand and are comfortable with the realities of living with bleeding disorders

**Goals** describe what the group wants to achieve, and are usually driven by the organization’s vision. Short or long term, they should be achievable to ensure that group members remain engaged and do not lose motivation. For example, wanting to raise \$100,000 is impressive, but you are more likely to reach or even surpass a more realistic goal. This does not mean that your group cannot have larger dreams, but that you are more likely to realize them through several smaller steps.

Your youth group’s goals could include:

- Organizing information sessions for group members
- Raising money for your local hematology unit
- Improving quality of life for members and their families
- Ensuring all local youth have visitors when recovering from a bleed

For more on **goals**, check out the article on page 18

For more on **fundraising**, check out the article on page 30

A youth group is a fun place to meet people who understand what it’s like to live with a bleeding disorder, but it is also a place of action. Make an important difference by joining or starting a youth group today!

*Originally published online February 2014*

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT THE FOUNDATIONS OF A YOUTH GROUP

Ask your youth group which of these they think would be most valuable for your group. Invite them to explain their choice(s).

- A A clear vision and goals
- B A great space to meet in
- C Assistance from the local hemophilia organization
- D Enthusiastic participants

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it, and ask them what they learned from it. Ask them what they expect to get out of a hemophilia youth group.

## WHAT’S NEXT?

### GETTING THINGS DONE

As your youth group grows, it needs structure to be successful. We will explore the roles and responsibilities available to potential members of the group’s management or steering committee.

# Youth groups: Who does what?

So you've started a youth group and have recruited some members. Congratulations! Now you need to make sure that your group will achieve its goals. You need structure! Establishing roles and responsibilities and clearly communicating who does what will help keep members engaged and go a long way towards ensuring your activities are successful.

## THE STRUCTURE OF A YOUTH GROUP

If you are affiliated with a National Member Organization (NMO), they may have an organizational structure for you to follow. If not, you will need to agree on a structure for your group.

The structure is not definitive; it will vary depending on the number of youth involved and the focus of the group. In larger groups several people may share a set of responsibilities, while in a smaller group one individual may take on a number of roles. Remember that you can always restructure if you need to, for example if needs change over time, or if the current structure is not working well.

Regardless of the level of formality, the youth group structure can be broadly divided into three levels based on the responsibilities of the volunteers: organizational leadership (e.g. president, executive committee, youth leaders), group management (e.g. working group or project leaders, youth managers), and general youth members. One example of an efficient youth group with a formal organizational structure is the youth group of the Hemophilia Federation of India (HFI). We will look at examples from this group as we explore each of the three levels.

## ORGANIZATIONAL LEADERSHIP

Youth at this level work closely with the formal governing body of the NMO to represent the youth perspective and to ensure that the youth group operates within the vision and aim of the organization. Volunteers may sit on boards or committees of the NMO (with full or limited membership), or participate in an advisory capacity. They also relay information from the larger organization to the rest of the youth group. For example, a Youth Member sits on the HFI Executive Committee. He or she organizes national youth initiatives, motivates youth managers from various chapters, and coordinates youth contributions to HFI periodical communications.

Examples of other positions at this level of the organization may include:

- **PRESIDENT:** leads the local youth group, directs the group management to ensure that the parent organization's vision and aims are being followed, and that appropriate activities are being undertaken.
- **VICE PRESIDENT:** works with the president to ensure that the youth group has the resources necessary to carry out its activities, and helps to identify and implement priority initiatives.
- **TREASURER:** oversees the finances of the youth group and reports back to the Executive Committee of the organization.

For more on **leadership**, check out the article on page 2

For more on **team work**, check out the article on page 9

## GROUP MANAGEMENT

These are the youth who run the actual youth group activities, who are in charge of a specific issue or who are responsible for an area of long-term involvement. They receive guidance from the leadership regarding the organization's values and priorities and the objectives of the project they have been tasked with. Drawing upon the rest of the youth group, they gather the resources and put in place the structure necessary to carry out the group's activities. Importantly, they also report back on activities and member views to the youth leadership. In the HFI youth group, Regional Youth Representatives coordinate activities and youth members in each region, and provide status reports on their region's group.

Other examples of positions at this level of the organization may include:

For more on **communication**, check out the article on page 24

- **COMMUNICATIONS MANAGER:** coordinates the production of youth-focused communications (newsletters, emails, annual reports, etc.).
- **FUNDRAISING LEAD:** organizes local fundraising events.
- **WORLD HEMOPHILIA DAY (WHD) PROJECT LEAD:** organizes local social and educational activities to mark this important day each year.

For more on **fundraising**, check out the article on page 30

For more on **pre-event planning**, check out the article on page 33

## GENERAL MEMBERSHIP

All members, whatever their level of involvement in the group, should be proud to be part of the bleeding disorders community, feel valued for their contributions, be respectful of other members, and help make the group a fun and friendly place to be. They should have opportunities to participate in the group's activities, whether volunteering to organize a particular project or taking part in activities organized by others. Members should feel welcome to suggest new ideas and projects to the group. As you plan for the future of your youth group, you will want to identify potential leaders and encourage them to take on more responsibility, to ensure the success of your youth group continues into the future.

Originally published online April 2014

For more on **member retention**, check out the article on page 21

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT YOUTH GROUP STRUCTURE

Ask your youth group which of the following reasons for an organization to have structure is most important. Invite them to explain their choice(s).

- A So that there is a clear hierarchy and everyone knows who the most important group members are
- B It isn't – people will naturally fall into the roles that best suit them
- C So that people know who is responsible for which tasks and who to go to for specific information or assistance
- D To improve productivity
- E C and D

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it, and ask them what they learned from it. Ask them what they think are the strengths of your youth group's organization or structure. How could it be improved?

## WHAT'S NEXT?

### TEAM BUILDING

How do you go about turning a group of people into a team working enthusiastically towards a common goal? How can a team ensure that morale stays high? In the next Young Voices article, read more about the power of a great team.

# Team work: The key to your group's success

For more on **vision**, check out the article on page 5

## WHAT IS A TEAM?

A team is more than a collection of people who happen to be in the same youth group, school, or workplace.

It is a group of individuals who are committed to each other and to working towards a common goal. They share a vision that provides motivation and guidance as they work, as a single unit, to achieve this goal together.

It is easier to build a strong commitment to this shared vision if each team member has a say in its development. Good leadership and collaboration are key elements in this process. It's also important to discuss this vision regularly with the team to help them stay on course, and as a reminder of the motivation for their hard work and effort.

For more on **leadership**, check out the article on page 2

It is also important to remember that each member has unique strengths, skills, and personality that can benefit the whole team. Through teamwork, trust, respect, and their shared vision, team members can truly bring out the best qualities in each other.

## CREATING A TEAM

When forming a team for a specific project, you'll want to consider each member's functional or technical expertise, but also their problem-solving and interpersonal skills. It's essential to include a variety of skills and personalities: bringing diverse perspectives together strengthens the team. It's important to recruit new team members in consideration of the overall purpose and needs of the team.

## WORKING TOGETHER

### *Synergy*

Team work is like baking a cake – combining different ingredients to create something totally different (and delicious!) and greater than just the sum of its parts. This is called *synergy*. This means that each individual, with his or her unique talents and skills, plays an important part in the success of the team. It's important to keep in mind that everyone contributes uniquely and synergistically in a team.

### *Cultivating collaboration, resolving conflict*

The most harmonious teams fit well together by connecting on a variety of levels. Improving a team's unity means working together in the most coordinated and cooperative way possible. Look at how the team collaborates and for ways of improving working relationships.

Teams are like a mosaic of different personalities, which can sometimes lead to disagreements and in some cases, conflicts. Conflicts can happen for many reasons – for instance, they may arise when two members have very different ideas for a project and are unable to reach a middle ground. Teams don't work well when there is unresolved conflict between its members, so it's important to address them as soon as possible.

A good idea for reducing conflicts is to set up **team guidelines**, which can help bring individuals into agreement about how they should treat one another and how issues are resolved. Discussions about mutual respect, good communication practices, each member's role within the team, and conflict resolution strategies are essential to the process of establishing team standards. All team members should be involved in these discussions and made aware of the resulting guidelines.

For more on **communication**, check out the article on page 24



### **Rewarding efforts**

When individuals do outstanding work, or the team achieves success, **reward** them for it. Having team members recommend colleagues for recognition is a good system as it involves everyone. Rewards don't have to be monetary or expensive; holding a celebratory get-together or just writing a thank you card can go a long way.

### **Bonding activities and team building exercises**

Creating team traditions such as eating lunch together once a week or holding seasonal social activities help forge bonds between team members.

Another fun way to create and strengthen relationships, to enhance trust, and to build understanding between team members, is through **team building exercises**. These exercises can range from attending group retreats to simply engaging your team in activities where teamwork is the key to success, like working together to solve a problem or **puzzle**.

Cultivating collaboration and resolving conflict help develop a better functioning, more successful team, while increasing the wellness of its individual members. A good team environment should heighten each member's sense of belonging, as well as strengthen the trust, goodwill, support, and friendship that exist between them.

*Originally published online August 2014*

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT TEAM BUILDING

Ask your youth group which of the following should be the objectives of a team bonding activity. Invite them to explain their choice(s).

- A** Competition between members to establish who is the strongest
- B** Joint problem solving to strengthen the functioning of the team
- C** Team members learning to do whatever the leader tells them to
- D** A fun social event where you don't have to really do anything

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Have them reflect on the group as a team and what their shared goal is. In groups of two, discuss what strengths and challenges each member brings to the team. Invite the small groups to share their findings with the rest of the group.

Ready, set,  
team-build!

Have the team agree upon the goal of the activity, then give them several choices of appropriate activities. Visit [www.teampedia.net](http://www.teampedia.net) for a list of activity ideas, or use them as a springboard for creating your own!

## WHAT'S NEXT?

### NETWORKING

A buzzword in the job market, **networking** is a valuable activity for youth groups and their individual members to participate in. Learn more about the importance of networking in the bleeding disorders community and get tips to ensure that it is a rewarding experience.

# Networking: Expanding your youth group's personal resources



A buzzword commonly used in job hunting, marketing, and social media, networking is crucial for the success of youth groups and non-profits. Networking is an information and service exchange between individuals and groups, and offers a fun and efficient way to share knowledge and inform people about your group's activities.

#### **WHY NETWORK?**

There are many benefits to networking in the bleeding disorder community. By building contacts you expand your perspective of the world through learning about the personal experiences of others and their strategies for living with a rare illness. Networking also

helps build synergistic bonds with many personal and practical advantages – from having a stronger voice to affect policy change, to sharing costs for organizing events and activities.

By enabling you to share knowledge with many different people, networking also helps to leverage the unique skillsets each person or group has to offer. For example, the youth group in one region may know more about lobbying and advocacy, while another may be more experienced at organizing community events or educational activities. The strength of networking is in opening the pathway to future collaborations between such diverse groups.

## WHERE TO NETWORK?

There are many opportunities for networking within the bleeding disorders community. Some of these include:

- Hemophilia chapter events in your area;
- Regional and national youth camps;
- Your local hemophilia treatment centre;
- Fundraisers for bleeding disorders organizations; and,
- The biennial Congress of the World Federation of Hemophilia.

For more on **fundraising**, check out the article on page 30

It's important to realize that networking shouldn't take place only within your own community. In order to change preconceptions and raise awareness of bleeding disorders, your group needs to expand its activities. In doing so, you may identify a good volunteer base for helping run events, professional services, or even sponsorship opportunities. By connecting with motivated individuals engaged in other issues you may learn of strategies and approaches not found within your community.

For more on **pre-event planning**, check out the article on page 33

Online networking is a great way to connect instantly to people all around the world. Through social media, you can create an online presence for your group, which can then be used to list events and workshops, gain peer support, encourage advocacy efforts, share information, and provide an online community for members. You can also connect with larger organizations like your national hemophilia association or the World Federation of Hemophilia through Facebook, Twitter, and LinkedIn.

Online networking can be a stepping stone to further connectivity, for example, through a telephone, Skype, or in-person meeting, allowing the parties to engage in greater expressions of support and interest, and to continue to build on their newfound personal and professional relationships.

Visit these links to connect with the WFH!



[www.facebook.com/wfhemophilia](http://www.facebook.com/wfhemophilia)



[twitter.com/wfhemophilia](http://twitter.com/wfhemophilia)



[www.linkedin.com/company/world-federation-of-hemophilia](http://www.linkedin.com/company/world-federation-of-hemophilia)

# NETWORKING TIPS

Quality over quantity matters in networking. Giving your business card to 300 strangers is less valuable than giving it to 10 people who really appreciate what you have to offer. People will also remember you better once you've built a connection with them, so don't be afraid to introduce yourself

For more on **communication**, check out the article on page 24

A good networker is a good listener, and vice versa. If you express genuine interest in people's work, they are more likely to open up and share their knowledge with you. If you're stuck in the conversation, remember the 5W questions: Who, What, When, Why, and how

Be yourself. Remember that networking is all about being genuine, building relationships, and seeing how you can help others

For more on **goals**, check out the article on page 5

It's easier to connect with people and groups who have similar goals and interests to yours. However, it's also enriching to meet people with different views – be focused about what you're looking for but keep an open mind

Have a clear understanding of what you do and why, and what makes your talents and skills stand out

Follow up with people you meet with a brief e-mail or note. A good way to further develop the relationship is to make a comment on a topic or article of mutual interest, or bring up something you talked about previously

When it's your turn to talk, be polite and tactful, not bragging and pushy

Do not say, show, or do anything online that you wouldn't do in real life. Online histories are practically impossible to erase, so think before you post

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT NETWORKING

Ask your youth group which of the following best describes networking. Invite them to explain their choice(s). Networking is ...

- A** All done online nowadays
- B** All about getting other people to help you, whether to find a job, raise money, or influence policy
- C** All about a mutual sharing of information and skills or services
- D** All about being extroverted – you need to be loud, funny, and smart to make a memorable impression

Originally published online October 2014

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Invite them to share, from their experience, some of the most productive ways to network in your bleeding disorders community. What challenges have they faced when attempting to network?

## WHAT'S NEXT?

### TIME MANAGEMENT

All too often, it seems like we don't have enough time to do everything that we need or want to be done. Learn how to use your time efficiently so that projects run smoothly and stress is kept to a minimum, and to delegate tasks so that work can be shared by the whole team.

# Time management: Scheduling your priorities

The best way to make the most of your time is to manage it wisely. An important first step in time management is understanding your priorities, or knowing that some things need to be dealt with sooner than others. Making a list of your priorities is helpful in highlighting what you should focus on first. This is an exercise that will often require a balance of things that you want to do versus things that you have to do. However, things may not always be so simple: how do you prioritize multiple things of great importance, like dinner with family, attending youth group, school work, and factor infusions? Here are some tips that can help.

## TIME MANAGEMENT TIPS

### *Time management log*

One handy way to plan ahead is to start a time management log – a specific, time-based, to-do list. Start by listing all the things that need to be done in the week, then rank your activities and tasks according to the following criteria:

- A – Tasks that are urgent and important
- B – Tasks that are important but not urgent
- C – Tasks that are neither important nor urgent

Plan when you aim to start and end each activity, then update with the time you actually spent on it. Remember to take into account any challenges or exceptions – like special events – that you need to include in your weekly plan.

ACTIVITY	PLANNED DURATION	TIME ACTUALLY SPENT	DATE/TIME	PRIORITY LEVEL (A,B,C)
Planning next youth group meeting	45 minutes	1 hour	Monday, 12:00pm	A
Homework	1 hour 30 minutes	1 hour	Monday, 5:00pm	A
Fundraiser for youth group	3 hours	4 hours (with clean-up)	Monday, 7:00pm	A
Swimming	1 hour	1 hour	Tuesday, 12:00pm	B
Choir practice	2 hours	1 hour 45 minutes	Tuesday, 6:00pm	B
Movie night	2 hours	2 hours	Tuesday, 8:00pm	C

### **Know your rhythm**

We all have a natural rhythm, which includes the need for rest and relaxation. Try to reflect on the times of the day when you have the most energy, and use these times to accomplish the most important tasks.

For more on **effective planning**, check out the article on page 18

### **Break it down**

Frequent breaks can improve mental agility. Use a timer to break down work into intervals (e.g. 25 minutes), separated by short (e.g. 5 minute) breaks.

### **Eat the frog!**

The American author Mark Twain said, “Eat a live frog first thing in the morning and nothing worse will happen to you the rest of the day.” There are tasks that we really don’t want to do and put off for hours, days, or even weeks: these are our ‘frogs’. If we tackle them first, we will have less stress, greater productivity, and a sense of self-fulfillment.

### **SELF MANAGEMENT VS. TEAM MANAGEMENT**

It is one thing to manage your own time, but what about making sure that a team is able to get work completed as efficiently and effectively as possible?

For more on **team work**, check out the article on page 9

Planning is an important part of this process. Being a good leader means you know your team – how they work, and how to motivate them. But you need to know how to delegate well so that the work is divided fairly and effectively.

For more on **leadership**, check out the article on page 2

### **Time management for your group – delegating tasks**

Delegating involves giving your team members the authority to react to situations without having to involve you. Entrusting them with tasks is important because you will not make the best use of your time by trying to do all the work yourself. By working with the unique strengths and skills of each team member, delegating tasks will ensure that things will get done faster and more accurately.

For more on **communication**, check out the article on page 24

## **STEPS TO SUCCESSFUL DELEGATION**

### **STEP 1**

#### **DEFINE THE TASK**

Know what the task is as well as the desired outcome, and make sure that the task is suitable for delegation.

### **STEP 2**

#### **SELECT THE INDIVIDUAL OR TEAM**

Which team member could best perform this specific task? What are your reasons for delegating Task A to Person B?

### **STEP 3**

#### **ASSESS ABILITY AND TRAINING NEEDS**

Are the team members capable of performing the task, and do they understand what needs to be done? Do you have enough time to train them if needed? Will they benefit from it?

### **STEP 4**

#### **COMMUNICATE**

Explain why the work is being delegated, and why you have selected them to do it. Communicate its importance and how it fits with the project or team vision, and precisely what needs to be done. Get feedback from the person or team to ensure that they understand, and of course, determine whether they agree to this assignment.

### **STEP 5**

#### **RESOURCES**

Determine what is needed to complete the work, taking people, location, equipment, money, and other related activities and services into account.

### **STEP 6**

#### **DEADLINES**

Discuss when you would like them to finish the task(s). If the task is complex you should explain the priorities and when review dates are. Whenever possible, strive to accommodate their abilities and preferences in deciding upon a realistic timeline. Check in with them at intermediate points to make sure things are on track.

### **STEP 7**

#### **SUPPORT AND FEEDBACK**

Establish with the team that if they come across problems, you will ask for their ideas regarding possible solutions, and help them come to a solution. Provide feedback throughout the task so they know how they are doing and whether they need to change anything. If it doesn’t go according to plan you need to review what happened with them.

***Being flexible – changing priorities  
& adapting to circumstances***

When you set priorities, whether for a task or toward a life goal, you should refer back to them to ensure that your efforts are really taking you in the right direction. However, as we grow and life brings changes, our priorities change too. Don't panic! Celebrate your accomplishments so far, then explore your new priorities and how you can work towards them.

For more on **welcoming change**, check out the article on page 38



Originally published online December 2014

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT TIME MANAGEMENT

Ask your youth group which of the following approaches to time management they think is most effective. Invite them to explain their choice(s). Which approaches do they tend to use?

- A** Work 18 hour days to complete the task just before the deadline
- B** Make other people do the work for you
- C** Create a list of priorities and work on them in order, enlisting help where appropriate
- D** The deadline is a week away, so forget about it then rush to complete it at the last minute

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Invite them to share any tips that they have for juggling multiple tasks both when working individually and when working in a team.

## WHAT'S NEXT?

### EFFECTIVE PLANNING

What constitutes a good plan, and why do you need one? To make sure that goals are met, you need a plan of action to help you get there. Find out more about planning, why it is important, and how best to do it.

# Effective planning: Mapping your path to success

Whether you have a problem to solve or a goal to reach, planning is the first step to action. Planning involves setting objectives, sorting out priorities, preparing timelines, and outlining strategies to accomplish them.

For more on **time management**, check out the article on page 15

Without a proper plan in place, it can be difficult to stay focused on your objectives and achieve goals within the desired timeframe.

It might seem like planning only happens in certain settings, like business meetings, during team sports, or when you are thinking about going on vacation. However, most people

plan on a weekly or daily basis without even realizing it. Think about going to school, for example. You have to decide when to get up, what to have for breakfast, and the best way to get there. Additionally, if you have an extracurricular activity like sports, you need to think ahead about bringing gym clothes to school that morning, what time you'll be home from practice, and how much time you'll set aside for homework and chores. Even if things become a part of your regular schedule or habit, you still plan your day around them.



## HOW TO PLAN

### Set goals – What do I want to achieve?

Setting objectives is the most crucial part of planning, as these are the end result that you are working towards. Whenever possible, goals should be specific, measurable, realistic, and time-targeted. What do you want to

achieve, and is it feasible in the given amount of time? How will you measure your success?

For more on **goal setting**, check out the article on page 5

If working with a team, set your goals together so that everyone feels motivated to achieve them.

### Forecast – What will I need?

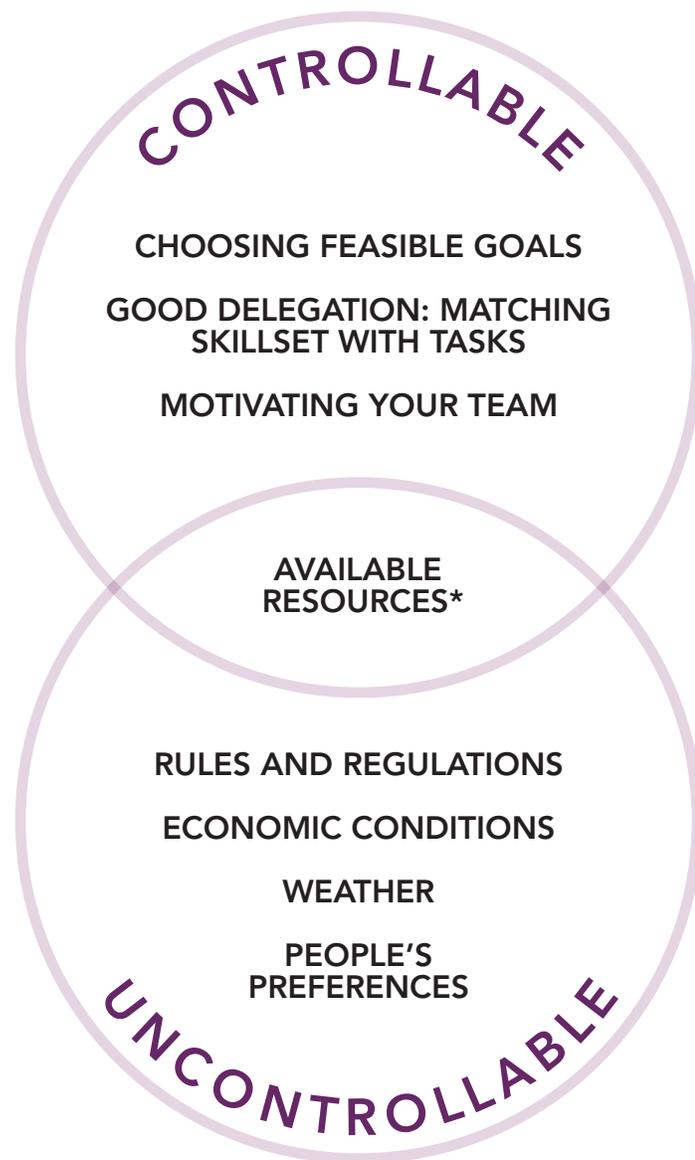
It's crucial to plan out ahead of time what you'll need to achieve your plan: time, resources, people, expertise, etc. An effective planner always thinks ahead about the uncontrollable and controllable elements that may affect their plan, acting as barriers or facilitators to achieving your goal. A careful analysis of these possible barriers and facilitators will help you to be prepared to react to situations that may develop as you implement your plan, and whether or not you can do anything about them.

### Brainstorm ideas – How can we achieve our goals?

Bring your group together and think about all the different ways that your goal could be achieved. Encourage all ideas, and empower each member to speak up. Make a note of each idea, and once they have all been written down, review each one and evaluate it for feasibility, as well as compatibility with your team's values and policies. This will enable you to develop a solid strategy for putting your ideas into practice, while staying on the track of your team's visions.

### Develop a timeline – When can we achieve our goals?

Develop a schedule that lists what needs to be done when. It should also take into account your barriers and facilitators and the impact they may have. Try to add a day or two's leeway between different tasks as a buffer. If everything goes to plan, you will be finished before the deadline, if not you won't end up seeking an extension.



\* Can sometimes be both controllable and uncontrollable

### *Have alternative plans of action*

While we can try our best, things rarely ever go according to plan. Be sure to plan for other possible options to reach your goal in case the chosen strategies take too much time or are unsuccessful.

### *Implement the plan*

Start working on the project. Team members should know their responsibilities, which member has been delegated to which tasks, where to get help and support, and the deadlines in your timeline. But also remember to be adaptable! Be sure to note any difficulties or challenges you encounter along the way, in addition to your successes.

### *Evaluate*

Through regular team meetings along the way, you will be able to assess whether your team needs to make adjustments. It also makes planning future activities easier and more successful.

### *Celebrate!*

Celebrate reaching your goal and reward your team for helping it come to fruition. Your hard work and focus deserves to be celebrated! Even if reaching your goal proves impossible, celebrate the advances that you have made.

## **LONG-TERM PLANNING**

While planning for and executing short-term projects can consume all of your time and energy, it is important to periodically consider your long-term goals. Develop medium and long-term plans to make sure that your everyday activities are helping to advance your overall goals and vision.

For more on **team work**, check out the article on page 9

## **TEAM WORK!**

Effective team work is key to your plan's success. Take the time to involve the team in objective-setting and plan development. Making the most of everyone's talents when planning who does what, and collecting feedback from everyone at the end of the project, ensures that each plan is even better than the last!

*Originally published online February 2015*

## **SHOW OF HANDS**

### **USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT EFFECTIVE PLANNING**

Ask your youth group which of the following principles they think is most important when setting the goals of an event. Invite them to explain their choice(s).

- A** The most daring possible. Aim big or you'll never get anywhere!
- B** You don't really need to set goals as everyone knows what the group wants and needs
- C** Realistic ones. This keeps people motivated and you are more likely to reach them
- D** Very small goals. This way they will be reached sooner and give members a sense of accomplishment

## **DIGGING DEEPER**

### **INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE**

Present the ideas in this article to your youth group, or invite them each to read it. Invite them to share their experiences of events that they planned that worked out well and others that didn't fully reach their goals. Can they identify any key differences between the planning in the two cases? Was it possible to work out an alternative plan if things didn't go as intended?

## **WHAT'S NEXT?**

### **MEMBER RETENTION**

Your youth members must be interested and involved in your youth group for it to be a fun, thriving place to be. Keep reading to discover ways to keep participation and motivation high.

# Member retention: Keeping your youth engaged

A youth group cannot exist without its members: you need to know how to keep people interested so they stay involved – member participation is what keeps the group alive. Without enough members, the quality of a youth group's activities and programs is diminished, the benefits of being part of the group are reduced, and it is harder for the group to achieve their mission.

## ASSESS YOUR SITUATION

Knowing what you can really offer members helps you to recruit new members and to deliver on promises. One assessment method is the *SWOT Analysis*. This examines the Strengths and Weaknesses within the organization, as well as external Opportunities and Threats.

<p>Fun activities Committed leaders</p> <p><b>STRENGTHS</b></p>	<p>No permanent venue Lack of funds</p> <p><b>WEAKNESSES</b></p>
<p><b>OPPORTUNITIES</b></p> <p>Foundation/ government grants WFH Youth Programs</p>	<p><b>THREATS</b></p> <p>Competition from other activities and youth clubs</p>

It's important to be honest when performing your analysis. While it can be hard to recognize where work needs to be done, doing so is the first step to making improvements. The SWOT framework shows what you should take advantage of (strengths and opportunities), and what you need to be prepared for (weaknesses and threats).

## GATHER DATA

Recording and managing membership data – through accurate and timely membership surveys – provides clear insight into your organization's current makeup. Age, gender, and contact information (e.g. mailing address, e-mail, place of residence) are examples of member characteristics you could document. Whether you record it in a large annual survey or in smaller collections, doing so on a yearly or semi-yearly basis is most useful.

Analyzing your membership information may reveal some trends you were unaware of: are numbers increasing or decreasing, do you have only very young members, are they all from one neighbourhood? This establishes the foundation for any change you may wish to pursue, such as increasing recruitment or reaching out to different groups of young people.

Be sure to include some open-ended questions in your member survey, like what motivated membership registration and what members value the most about the group, or in the case of de-registrations, what made them decide to leave. These answers can help identify what you could do to better accommodate member needs.

## ENSURE INVOLVEMENT

For more on **democracy**, check out the article on page 27

There are many ways to promote active youth involvement in the group, this being the key element for member retention in youth groups. Empower members by encouraging *equal participation* in the group's development and decision-making processes. This will in turn help members to feel a sense of *ownership* within the group. Contributing to the team's overall vision and goals, and having those contributions valued and recognized, will solidify a feeling that this is their youth group.

*Identify and address the needs* of your members through Q&A sessions and mentorship programs. For instance, young people with bleeding disorders may have questions and worries about having intimate

relationships, starting a family, and embarking on successful careers, all while managing their medical condition or struggling to access comprehensive care themselves. Providing information and being responsive to their needs helps to establish an *emotional connection* and shows that you care about the members as people, first and foremost. If youth feel that they can trust staff and fellow group members, they are more likely to feel supported and in turn, continue to show their support.

For more on **team work**, check out the article on page 9

Create and strengthen a sense of community by organizing team activities. Youth camps are one great example; they provide a fantastic environment for members to bond, have fun, and meet other young people living with a bleeding disorder.



For more on **communication**, check out the article on page 24

Always prioritize **clear communication** so that everyone knows what is happening, what to expect, and what is expected of them. If people are out-of-the-loop they may feel disconnected from the group and its activities, and be less likely to participate. **Showing appreciation** for hard work, effort, and involvement makes a big difference. Recognize and encourage self-motivation, development, and dedication to the group, this inspires people to thrive in the organization. Always celebrate accomplishments together as a group!

For more on **who does what**, check out the article on page 7

For more on **public relations**, check out the article on page 10

It's important to recognize potential and help people to be their best. Whenever possible, **train** members in areas such as leadership, team building, communication, media literacy, grant writing, and government lobbying. This provides them with the tools to succeed, within the group and elsewhere, and ensures you have an educated, empowered group of thinkers who can confidently perform their tasks.

For more on **members**, check out the article on page 5

Carefully consider your group's situation and needs before deciding on member retention tactics, and develop solutions that encourage and value youth involvement and empowerment. Remember, being in tune with member motivations, inspirations, and happiness is key to ensuring active participation and to enabling your community to flourish. After all, a youth group really is all about the youth members!

Originally published online April 2015

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT MEMBER RETENTION

Ask your youth group which of the following approaches they think is most important for maintaining the interest of youth members in the group. Invite them to explain their choice(s).

- A Have a lot of interesting and relevant activities
- B Make the meeting place fun, colourful, and equipped with the latest technology
- C Encourage member involvement in running the group
- D Ignore negative comments and penalize bad behaviour

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Ask them each to propose two questions you could include in a membership survey, and to explain what important things those questions would help you to learn.

## WHAT'S NEXT?

### COMMUNICATION

Letting people know what you expect of them and providing feedback on their work can be more complex than it sounds. Your youth group might be required to provide minutes of meetings to your national hemophilia society or local chapter. Find out what to include in minutes as well as how to give constructive, effective feedback.

# Effective communication: Forging deep connections

Communication is an integral part of being human. It's how we share information and feel connected to one another. But effective communication is more than just an exchange of information; it's about expressing who you are as a person and the emotions and intentions behind what you're trying to say. Good written and spoken communication is instrumental in strengthening our relationships with others, both personally and professionally. Effective, collaborative communication is essential to the success of any team, including your youth group.

## EFFECTIVE, COLLABORATIVE COMMUNICATION

### *Providing feedback*

**Constructive feedback** can help individuals to become better at what they do by highlighting their strengths and by bringing their attention to things that can be improved. The aim of



constructive feedback is to **help** individuals by expanding their knowledge of themselves and the impact they have on others – it is not an opportunity to degrade or insult them. Because feedback can be about personal things that people feel strongly about, it is not enough to merely have good intentions; feedback must be communicated effectively and sensitively. Balancing the negative with plenty of positive is key.

## CONSTRUCTIVE FEEDBACK

- Constructive feedback is information-specific, issue-focused, and based on observations
  - Wherever possible, use specific examples and avoid exaggeration and judgments
- Give feedback from *your* perspective. This avoids labeling the person
  - "You always take credit for my work" is not as helpful as "I was surprised and hurt that you didn't mention my contributions."
- Don't give feedback through e-mail or text message. Whenever possible, do it face-to-face, or by telephone
- Express appreciation in positive feedback situations
- Express concern in negative feedback situations. This shows you care and provides a level of sincerity. Try to avoid expressions of anger, frustration, disappointment, and sarcasm. These have a destructive rather than constructive impact
- In the case of negative feedback, suggest concrete next steps. This ensures that you both know what needs to be done to improve the situation. Listen actively to what the individual says and encourage them to come up with solutions. Follow up to see how performance is improving
- Use constructive feedback regularly to acknowledge good performance, and to balance any negative. It can be easier to notice failings than good work, so make an extra effort to look for the positive

## MEETING MINUTES

### *Writing meeting minutes*

Recording what goes on in your group's meetings ensures that you have something to refer back to if you need to remember key points of that discussion. *Minutes* are a written record of meetings and the decisions taken within them. They are helpful because people can forget what was said, what timelines were agreed upon, or what ideas were shared. They also inform absent members what took place during the meeting, while documenting any action items for the immediate and more distant future.

### *Who records them?*

Usually a designated participant or participants will take minutes at each meeting; the task can be rotated among group members. If it's your turn to take minutes, ensure that you receive a copy of the agenda ahead of time, so that you can familiarize yourself with the attendance list and the topics to be discussed.

### *What to record*

"Minutes" is perhaps not the best name for this record as they do not document every single thing that happens each minute, but rather the essence of what happened. The following information is usually included:

### *Distribution of minutes*

The role of the official "minute taker" may include the distribution of the minutes. Ensure that the Chair has reviewed them before circulation. It is good practice to keep a record of the distribution of minutes, even if this isn't a requirement in your organization.

## WHAT TO INCLUDE IN MINUTES?

- Time, date, and place of meeting
- Name of organization (your team or committee name) and minute taker
- Agenda or list of items to be discussed
- Those present. If you don't know everyone, use the attendance list. When typing out the minutes, start with the President/Chair's name before listing all present. Referring to people by their initials elsewhere in the minutes saves space and time
- Those absent, often referred to as Regrets or Apologies
- Approval of the previous meeting's minutes, and any matters arising from them. To become an official record, the previous meeting's minutes must be approved, seconded, and voted to be a true and accurate record
- Main points discussed and decisions taken for each item on the agenda, for example:
  - Voting outcomes
  - Ideas
  - Actions taken or agreed upon
  - Next steps
- AOB – Any other business (items not on the agenda but that are brought up as the meeting closes)
- Date, time, and venue of next meeting

## OPEN THE DOOR TO PROFOUND CONNECTIONS

Practicing effective communication in a youth group setting has many advantages. It gives team members a valuable forum for expressing their feelings and inner thoughts, which can in turn help you to better understand who they are as individuals, and as part of the team. It also allows members to

express their appreciation for each other and their hard work, while highlighting things that require improvement or change. A crucial part of team building, the right kind of communication, free of judgment and harshness, opens the door to a more profound connection with others.

For more on **team work**, check out the article on page 9

*Originally published online June 2015*

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT COMMUNICATION

Ask your youth group which of the following reasons for recording meeting minutes is most valuable to them. Invite them to explain their choice(s).

- A** So that people who weren't at the meeting know what happened
- B** So that you can hold people to what they said they would do
- C** As an accurate record of what took place
- D** All of the above

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Invite them to reflect on a time when they had to share negative feedback with a friend, family member, or team mate. How did they go about communicating the feedback and did they learn anything from the way the person reacted?

## WHAT'S NEXT?

### DEMOCRACY

How can you ensure that all members feel involved in your youth group decisions? Should the group's actions and information be made available to all members, the government, and even the general public? Learn more about democracy and transparency in an organizational setting in the next *Young Voices* article.

# Democracy: We're in this together!



Image courtesy of nongpimmy at FreeDigitalPhotos.net

## DEMOCRATIC PRINCIPLES

Democracy comes from the Greek words “demos”, meaning the people, and “kratia”, meaning power, or rule. The idea of everyone having a say in what happens in their towns, cities, and villages can also be applied to organizations. A democratic organization is based on freedom rather than control or fear. A democratic organization values and increases human potential.

Instead of a few members having absolute control, a democratic organization encourages every member to be equally involved in the decision-making process. Simply by virtue of being a member of the organization – or a citizen in a society – one is entitled to be treated as an equal.

For more on **communication**, check out the article on page 24

Communication in a democratic organization involves all members. Each person's input is valued on its own and as part of the greater vision of the organization.

Applying the principles of democracy to your organization can have great benefits. A democratic organization aims to achieve productivity without being utilitarian. This means that members and their skills are not seen as a means to an end, to be exploited for the benefit of the organization – rather, they are valued as people first. A truly democratic organization will encourage members to contribute while providing them the support they need to be their best. As a result, democratic organizations have a huge potential to come up with more creative ideas, while ensuring the happiness of their members. Feeling valued and having a say in your group's activities makes you feel like you belong!

## APPLYING DEMOCRATIC PRINCIPLES TO ORGANIZATIONS\*

- Members rule through a decision-making process that they've established by a vote
- Ideas come from the members and are presented to the group assembly for decision making
- Leaders are chosen from amongst the members through a free and fair election process
- Checks and balances between the leadership and the members are established in the governing documents
- All members are equal — they have equal rights and responsibilities
- The organization is run with impartiality and fairness
- Everything is accomplished in the spirit of openness, not secrecy
- Members have the right to resign from office or from the organization

\*Robert McConnell Productions. *Robert's rules of order simplified and applied*. 2nd ed. Indianapolis, IN: Webster's New World. Wiley Publishing Inc. 2001.

## TRANSPARENCY

*Transparency* is an important feature of democracy. A transparent object is one we can see through, and in terms of a government or organization this implies openness, accountability, and honesty. It requires regular and open communication within the organization, through regularly held meetings, disclosure of financial statements, clarity about corporate sponsors, and openness to financial audits and information requests. Increasing transparency is inherently about building trust and loyalty among group members.

*Organizational transparency* moves away from a “members only” attitude to welcoming non-member and public input. This means embracing open access to information and encouraging new membership. Transparency is important to ensuring that your organization’s activities are honest and devoid of secrecy. It also means sharing your group’s vision and plans with those who may not be directly involved in its decisions.

For more on an **organization’s vision**, check out the article on page 5



You must be prepared for some challenges when providing open access to information, for example, the information may be misunderstood or misrepresented by others. Discussions and good judgment are essential when deciding how your information should be relayed to the public. It is just as important to determine what information needs to be kept private – such as medical and personal information – in order to respect members’ privacy and confidentiality.

## TRANSPARENCY CHECKLIST

The following items should be considered in your organization’s transparency plan:

- **OPEN BOARD MEETINGS:** Post the location, date, and time of open meetings on your group noticeboard well in advance
- **FINANCIAL DISCLOSURE:** Consider posting audited financial statements on your website
- **FREEDOM OF INFORMATION:** Be aware of “right to know” rules that guarantee access to data (For more information visit [www.rti-rating.org](http://www.rti-rating.org))
- **ANNUAL AUDITS:** Have accounting and auditing firms check that your accounts are in order, and that no financial laws are being broken including tax laws
- **ANNUAL REPORTS:** Compile information including accounts of group activities and programs throughout the year, fundraising efforts, and how those monies were used
- **STRATEGIC PLANS AND PRIORITIES:** Distribute these key statements to group members and post them publicly on a noticeboard or website
- **INFORMATION ABOUT BOARD OF DIRECTORS AND KEY STAFF/MEMBERS:** Make names and contact information of these individuals available on your website, noticeboard, or newsletter

In principle, operating on trust, transparency, and member involvement should reduce the need for layers of bureaucracy. This, in turn, minimizes waste and increases efficiency –

another advantage of operating a transparent, democratic organization.

For more on **who does what in a youth group**, check out the article on page 7

Boosting efficiency, improving member

involvement, and increasing creative output are just a few of the advantages of a democratic organization.

Although it may be hard to switch from a different model, the benefits of democracy and transparency are worth the

efforts. Valuing members and enhancing team work through a truly democratic

structure creates a more fun, supportive community that is full of potential and great ideas, and more likely to successfully reach its goals!

For more on **team work**, check out the article on page 9

For more on **member retention**, check out the article on page 21

*Originally published online July 2015*

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT DEMOCRACY IN A YOUTH GROUP

Ask your youth group which of the following statements best describes a democratic organization. Invite them to explain their choice(s).

- A** Everyone has to agree before a decision is made
- B** Members can express their opinion, but the leader makes the final decision
- C** All information regarding group activities and members is made public
- D** All members have equal rights and responsibilities

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Invite them to share experiences of an organization in which they felt they had an equal voice. Do they feel this is the case in the youth group? Can they think of ways to overcome challenges to equal participation by everyone?

## WHAT'S NEXT?

### SPREADING THE WORD

Your group is doing great things for its members and the bleeding disorders community, and you want people to know about it. Or maybe you have established a financial goal for a good cause and want some support. In the next *Young Voices* article, find out how to approach public relations and fundraising strategies.

# Public relations and fundraising: Furthering your cause

## WHAT IS PUBLIC RELATIONS?

It's good to let people know about your youth group, especially when you have an upcoming event or recent projects you want to showcase. Public relations, or PR, is the management of your public image – more specifically, how it is defined, maintained, and displayed to the public. This often involves reporting by various media as well as your own public presence.

The foundation of public relations is to know your audience and tailor your message accordingly. Keeping your message consistent is also key – being clear on who your group is and what you stand for will help maintain positive public opinion. The online world presents many new PR opportunities with various avenues for spreading the word, from social media to blogging.

For more on **democracy**, check out the article on page 27

## FUNDRAISING ESSENTIALS

Your group has a mission, but do you have the financial means to see it through? Every functioning organization needs a plan for raising funds and resources to ensure its longevity. Be creative and resourceful! Network with local communities and other bleeding disorder organizations, and be sure to look into government grants and corporate sponsorship.

For more on an **organization's mission**, check out the article on page 5

For more on **networking**, check out the article on page 12

### *Do your prep work*

Identify why specific resources are necessary for your organization's mission and strategic plan, when designing your fundraising campaign. Creating a portfolio for potential donors can help. This could include evidence of past accomplishments, effective management and leadership of your group, and the organization's relationship with the community, demonstrating how the resources will translate into benefits.

For more on **leadership**, check out the article on page 2

## TIPS AND TRICKS FOR A SUCCESSFUL PR CAMPAIGN

- Learn the art of writing a good press release, or ask for help from someone who can
- Telephone key contacts before sending your press release. You can give them more context, which helps to get the media interested
- Don't call during journalists' deadlines (usually 2pm onwards), and remember that some media is planned weeks or even months in advance of its release date. For example, December holiday issues are often planned in August or September
- Don't give up – your PR efforts may not always be successful. Keep at it, and try looking for a more newsworthy angle

## ONLINE FUNDRAISING

**ONLINE FUNDRAISING** has become increasingly popular as it offers unparalleled access to new audiences at relatively low cost. A website for your organization would be ideal, but a Facebook or other social media presence is a great start.

**CROWDFUNDING PLATFORMS** are websites that pool multiple small donations to achieve a larger goal.

FundRazr [www.fundrazr.com](http://www.fundrazr.com), Fundly [www.fundly.com](http://www.fundly.com), and Rally [www.rally.org](http://www.rally.org) are examples of online fundraising sites that may be of interest to not-for-profit organizations.



Image courtesy of Stuart Miles at FreeDigitalPhotos.net

### **Legal and tax issues**

Legal and taxation factors must be considered when raising money. Financial advisors, or your Treasurer, can help your group understand these laws. When planning the fundraising activity itself, don't forget about insurance issues and potential tax relief for donors.

### **Know your assets**

Identifying the group's assets gives you an understanding of the resources you already have. Assets aren't always about money. They can include skills, talents, and connections. For example, if you have several members who are accomplished bakers, you could hold a bake sale to raise money for an event. Someone in your group may have access to a roomy car that can transport your group to networking events. And don't forget that volunteers are extremely valuable assets! Friendships and connections are invaluable to success in life – this is fundamental to the idea of **social capital**.

### **Fundraisers**

There are many ways to raise money. Fundraisers can include social events like a dance, sporting activity, concert, or conference. It's important to announce to participants and sponsors of these events exactly what the donations and profits will support.

**Grants** are often offered by foundations, trusts, and government agencies. Guidelines and requirements should be available to potential applicants, who then submit a proposal outlining the details of the project, along with a completed application form.

**Corporations and local businesses** can be contacted for monetary donations, but they are also potential sources of expertise, volunteers, services, or products. For example, a business might be willing to sponsor events, provide prizes for raffles, or let you use their venue for free. Forming a relationship with a company's decision makers may seem challenging, but don't forget the power of your network.

For more on **pre-event planning**, check out the article on page 33

For more on **executing and assessing event plans**, check out the article on page 36



It is crucial to let all potential donors know how their contribution will help your group achieve success. Be as specific as possible. “Your \$50 will enable young children in Peru to see a physiotherapist, helping them recover faster from bleeds,” is far more powerful than just saying that your group increases access to treatment for bleeding disorders. Updating donors via e-mail or newsletters on how funds from different campaigns were spent shows appreciation and keeps them interested in the cause. It may even encourage them to become regular donors.

Another source of funds is *individual donors*, whether they contribute regularly through membership fees, or via one-off donations. Understanding why people donate is the first step to successful fundraising and helps personalize your approach. New donors may be reached through advertisements in newsletters or magazines, social media, going door-to-door or approaching people on the street, or in special cases, through media coverage.

Everyone needs help at some point in their lives, whether in the form of skills, time, services, or money. A youth group is no exception – in fact it is likely that you will need assistance in several areas. Figuring out how to successfully ask for funds or other contributions is always challenging, but it’s also absolutely necessary to ensuring that your organization achieves its mission. Don’t be too disappointed if people don’t give right away – keep trying and think of other ways to showcase your project or solicit donations.

*Originally published online September 2015*

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT FUNDRAISING AND PUBLIC RELATIONS

Ask your youth group which of the following they think is the best way for the group to raise money. Invite them to explain their choice(s).

- A Only ask people you already know who have shown commitment to the cause
- B Reach a wider audience by approaching the media
- C Head online and try crowdfunding your project
- D Organize a large event and charge a high entrance fee

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Ask them to share examples they have seen of ways in which organizations have successfully retained past donors or recruited new ones. Could any of these strategies work for your youth group? Are there any particular challenges these strategies might run into?

## WHAT’S NEXT?

### EVENT ORGANIZATION

Planning and running an event can be stressful, but it can also be lots of fun, especially if you get a whole team involved! Find out more about preparing to host an event, from setting goals to putting together your event team, and getting the word out in the first installment of the two-part *Young Voices* article on event planning.

# Event planning part one: Pre-event, setting the stage

Organizing an event is a great way for a youth group to work collaboratively towards a concrete and meaningful goal. It has many benefits, such as discovering more about programs and events in the bleeding disorders community, building networks, finding new members and volunteers, and gaining new life experiences. Whether organizing a small group activity or a large multiday conference, there are several important principles to event planning.

For more on **networking**, check out the article on page 12

## IDENTIFY THE RATIONALE

Everything starts with an *idea*. Whether this comes from an individual or is a group decision, use it as a starting point for brainstorming. You can draw on events you've attended for inspiration and tips on event organization, like booking a venue or structuring your program.

For more on **goal setting**, check out the article on page 5

Knowing *why* you want to organize an event is essential to its success – you need to set a goal to work towards. Wanting to make a change, raise funds, or simply have an educational or fun event are all valid reasons to start planning one, but you should be able to identify one clear objective.

Once the goal is set, you need to get the youth group on board. Present the idea with enthusiasm, but be prepared for questions by developing the idea and having solutions ready for possible problems. Be flexible and adapt your

For more on **team work**, check out the article on page 9

plans to incorporate the members' ideas, then it becomes their event too, not just everyone trying to follow your singular vision.

## DO THE GROUNDWORK

Having decided your *WHY*, work as a team to *determine the other W's*: *WHAT* kind of event it is, *WHOM* it is for, and *WHERE* and *WHEN* it will be held. The event objective helps formulate its primary content and will guide the *who* of your audience.

Thinking about the format of the event will answer your *what*. Is it a one-track conference (one session at a time), multi-track (several parallel sessions), or a half-day workshop, for example? Once you know the content and format, you can create a loose schedule with an idea of how long sessions should be and whether to include meals.

For more on **effective planning**, check out the article on page 18

Start to brainstorm potential venues. Consider mobility issues, not just within the venue itself but also in getting there. Think about prospective speakers and/or workshop leaders. You must have an idea of *when* you would like to host the event in order to book speakers and the venue. Be sure to give yourself enough time to plan properly. Be aware of statutory and religious holidays, and check dates with key participants.

The success of your event depends directly on the ability of your event planning team to fulfill their roles. If you are planning a smaller event, the details of the roles may be simpler, but you still need someone to be responsible for each area.

For more on **who does what in a youth group**, check out the article on page 7

## ROLE CALL! THE EVENT PLANNING TEAM

### EVENT MANAGER (USUALLY THE TEAM LEADER)

Directly manages and organizes the work of the entire team, participating in all phases of preparation, execution, and evaluation. Provides advice, support and assistance, delegates tasks, and deals with conflicts.

### FINANCES

Prepares the budget and gathers necessary funds. Coordinates the material and financial needs of team members, keeps track of payments, and creates the final financial report.

### PROGRAMMING

Plans the whole program, from breakfasts to conferences, workshops, and activities. Contacts speakers and participants, liaises with the logistics, accommodation, and technical support teams, plans evening events, and makes contingency plans.

### ACCOMMODATION

Finds suitable accommodation for all event participants, bearing in mind any mobility issues. Everyone should ideally stay in one hotel or hostel, or at least in close proximity to one another. This person may also be responsible for lunch and dinner reservations.

### LOGISTICS

Responsible for transportation of event participants to the venue and around the city during the event, plus for any excursions or sight-seeing activities, if applicable.

### TECHNICAL SUPPORT

Prepares halls and meeting rooms, and ensures that all necessary audio-video equipment is present and functional.

### WEBSITE

Maintains and updates event website. They are not responsible for content, but for functionality.

### PUBLIC RELATIONS (PR)

Targets and contacts media to increase interest in the event, the youth group, and your cause. Student and hemophilia chapter newspapers and newsletters are a great place to start.

For more on **fundraising**, check out the article on page 30

For more on **public relations**, check out the article on page 30

## DESIGN YOUR PROMOTIONS

**Branding** your event can attract greater interest and differentiate it from others. Brainstorm names with your objective in mind and create a tagline – a short, catchy slogan that describes the event. Finally, design a logo to represent the event. It will be key to your publicity efforts and can be printed on promotional items.

## RECRUIT SPONSORS

There are three categories of **sponsorship**: **media**, who help promote the event; **partners** who share resources, and **financial contributors**. In addition to corporate sponsors you could approach national and local government; affiliated organizations who may want to sponsor a dinner or presentation; pharmaceutical companies who could sponsor a treatment area; your regional or national tourist agency; restaurants that could offer discounts on group dinners, etc.

## STAY ON TOP OF THE DETAILS

Create a **master plan** that includes all aspects of the event, such as:

- Venue, logistics, and catering management (booking, contracts, permits, insurance, etc.)
- Speakers/presenters (identifying, confirming, logistics, management)
- Activities and entertainment
- Publicity/promotion (on- and off-line, e.g. website, banner ads, event calendars, PR, social media, etc.)
- Registration (invitations, online and on-site registration, including payment)
- Sponsor and partner management
- Volunteer management

Use a **checklist** to ensure that all essential tasks get done on time.

There are many moving parts involved in organizing a successful event, but with good planning and team management, you will get there. The better you plan out and manage the details, the better your team will be able to enjoy learning new skills and working together towards a worthwhile goal.

*Originally published online November 2015*

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT PRE-EVENT PLANNING

Ask your youth group which of the following approaches to event planning is most likely to be successful for your group. Invite them to explain their choice(s).

- A Have a lot of money or great top-rate sponsorship
- B Start from a good idea and work as a team to make it into reality
- C Take time to plan thoroughly and keep track of all event tasks
- D Have a lot of volunteers to do most of the work at the event

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Have your youth group members reflect on what they feel has been the groups' most successful event to date. Invite them to discuss what they felt was challenging about the organizing process, and what allowed them to overcome those challenges.

## WHAT'S NEXT?

Preparation is a big part of making sure that your event goes smoothly. However, there are still many things to do once participants arrive. Keep reading to find out more about successfully running your event.

# Event planning part two: Execution and assessment

The participants have arrived and the big day is here. Making sure your event runs smoothly depends mostly on the extensive planning and preparation detailed in the preceding article, but there is much you can do to minimize mishaps and maximize success on the day.

For more on **team work**, check out the article on page 9

For more on **pre-event planning**, check out the article on page 33

## VOLUNTEERS

A well-prepared team of volunteers is crucial to your event's success. Their role can range from on-site registration to staffing the information booth, ensuring that guests have everything they need, assisting with technical production, and running errands. Ensure that your volunteers have a good understanding of safety rules, for example, being aware of any participant food allergies and knowing the location of fire exits. Make sure they receive all necessary information and training ahead of the event. Treat your volunteers with respect – both you and they should be clear about their responsibilities. You want their experience to be a pleasant one.

## WELCOMING GUESTS

The Logistics team should know the exact times that participants will arrive, and if needed, arrange transportation to the venue. As guests arrive, greet them with a smile! Usher them into the venue and ensure that your team provides support to those who require assistance (e.g. the elderly, people with disabilities). If you have invited special guests like speakers, performers, or dignitaries, dedicate one or two volunteers to hosting them. A fantastic way to kick off your event is to arrange a small welcome reception where people can mingle and meet in an informal setting.

## TEAM MEETINGS

For multi-day events, your team should meet at the end of every day to discuss tasks for the following day, making sure everyone knows where they need to be and what they are responsible for. You should also go over what happened that day, both the positives and the negatives, and whether any changes need to be made.

Being well organized and prepared is vital, but it's equally important to be adaptable to change. Unexpected challenges will arise, but if you are flexible and resourceful, your team will find solutions to them. Encourage each other! In hectic times, it can be difficult to remember how important every single team member is to the success of the event – even the smallest encouragement can go a long way!

## SAY CHEESE!

Document your event with photographs, audio recordings, videos, and through social media or your organization's blog, so that those who couldn't make it can still share the experience. In addition to being a great way to remember the event, this record can serve as a reminder of the hard work and talent of everyone involved. It also provides a great tool for reviewing the event, for improving future programs, and for promoting your next activities. You can even publish videos on YouTube, or invite the local media to spread the word about your event and your organization – but remember to get permission from your guests!

For more on **effective planning**, check out the article on page 18

For more on **public relations**, check out the article on page 30

For more on **democracy and accountability**, check out the article on page 27

## PARTICIPANT DEPARTURE

Especially for multi-day events, the Logistics team needs to know what time each participant is leaving, and arrange transportation to departure points. Thanking delegates at the close of the event, and providing a photograph of all the participants and organizers along with a certificate of attendance, is a nice touch. Before they leave, ask participants to complete a feedback form, on paper or online. Once all the participants have left, hold a short team meeting to celebrate the event's success and thank everyone for their contributions.

## ASSESSMENT

Give your team enough time to recharge their batteries, before getting together to review the success of the event more critically. Consider participant feedback as well as individual team assessments.

*Participant feedback* is best when obtained immediately after the event, usually through an anonymous questionnaire. This should contain both multiple-choice and open-ended questions about all aspects of the event, from the accommodation and food to the program, logistics, and activities. Ask for comments about both the positive and negative aspects of their experience!

*Team feedback* consists of a series of honest individual and group

assessments. Be constructive in your feedback. Evaluate whether the objectives of the event were reached (e.g. concrete goals like the amount of funding raised, or soft goals like the promotion of your group), the concept of the event and how it was carried out, possible improvements in team and individual performance, and any problems encountered and possible reasons for them. Invite feedback and suggestions from your team members. They may have heard or seen things that you missed. As the individuals carrying out the tasks essential to the event's success, they often have great ideas for improvements.

Write a report that your group can keep as a learning tool, and send a copy to the Executive Committee. Your experiences can be further shared in the group's newsletter or in the local media.

Although organizing an event can be hard work, it is an unforgettable experience that brings a whole host of benefits. Learn from each event, and use it as inspiration and motivation for other projects. Most importantly, have fun together!

Originally published online December 2015

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT POST-EVENT FEEDBACK

Ask your youth group which of the following approaches to assessing whether an event was successful or not would be best to use with your group. Invite them to explain their choice(s).

- A Determining whether you reached your goal or not
- B Counting votes from participants as to whether the event was successful or not
- C Working out if participants had a good time
- D Collecting positive and negative feedback from the team and participants

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Invite your members to share examples of memorable feedback that they received following events they have been involved in. Could the feedback, positive or negative, be helpful in improving the planning of a future event?

## WHAT'S NEXT?

### WELCOMING CHANGE

Working to achieve your group's vision and goals is important, but what happens when your goals are no longer in line with the group's needs or reality? Find out more about setting new targets and adjusting mission statements in the final *Young Voices* article.

For more on **effective communication**, check out the article on page 24

# Welcoming change: Evolving together

With a clear vision and shared values, your youth group is highly motivated to work together towards your short and long-term goals. But life is ever changing, and you may find that your team's initial goals are not as relevant today, or as inspiring, as they once were. It is important to recognize when it is time to re-evaluate and embrace change.

For more on **values, vision, and goals**, check out the article on page 5

## VALUES, VISION, AND GOALS

In the second article in this series, “Fun, friendly, life-changing: youth groups,” we examined the concepts of values, vision, and goals as they pertain to organizations.

**Values** are qualities that are considered worthwhile. They represent the group's highest priorities and provide a great source of motivation. **Vision** is about the future – what your group wants to be or the kind of world it would like to be part of. **Goals** describe what the group wants to achieve, and are usually driven by the organization's vision. These three components are key to the direction of your youth group, and like every aspect of life, they may also evolve and change. This does not constitute a failure; it simply reflects the reality of changing circumstances.

## NEW GOALS

You may find that your established goals are unattainable, no longer reflect the priorities of your members, or are no longer challenging. New goals can be set at any time, but the following situations are common:

### TIME FOR A CHANGE

- **UPON ACHIEVING A GOAL:** Reflect on how the goal was set and the efforts that went into accomplishing it, as you set new attainable goals
- **AT THE END OF THE FINANCIAL YEAR:** Numbers can speak louder than words, and seeing your organization's financial situation on paper can be a catalyst to setting new goals
- **WHEN THINGS GO WRONG:** No matter how much you prepare, life doesn't always go according to plan. Learning from mistakes is a great way to redefine objectives
- **FOLLOWING GROWTH:** When your team recruits new members or experiences a significant financial boost, you may have the skillsets or resources to take on projects that were previously not possible
- **WHEN ON VACATION:** Sometimes when you are the least focused on challenges, new ideas and a clearer perspective allow you to propose new solutions

Although the end of the year seems like a natural time to define new objectives, if your group has slower months in the year, these are also a good opportunity to reflect on goals, to focus on what is working, and to consider additional projects.

[Planning and initiating projects: A guide for emergent NMOs](#) (available at [www.wfh.org](http://www.wfh.org)) provides strategies for team priority setting.

### NEW VISION

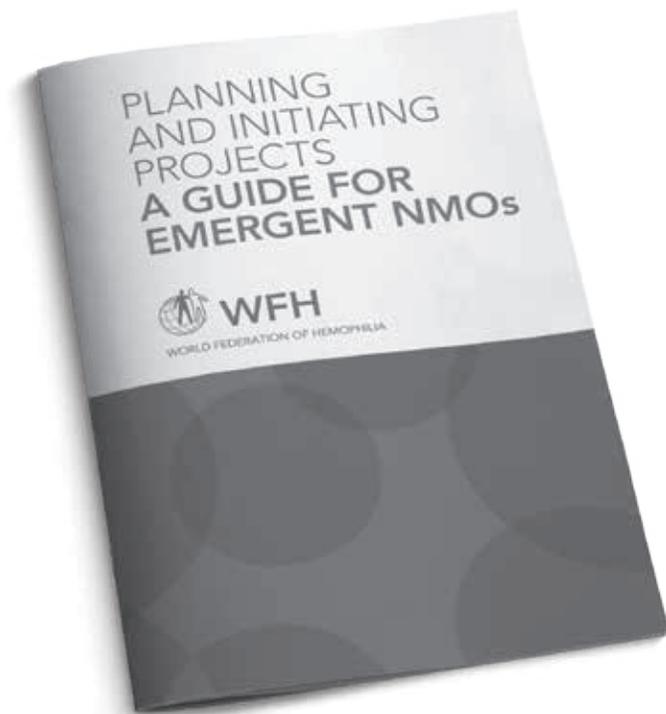
Changing your organization's vision may be complicated, because it forms the very core of what your group aims to achieve. However, this doesn't mean that it cannot or should not be revised.

Your vision should reflect the evolution of your youth group as well as its current reality. If, for example, the group was founded by a few teenage boys with hemophilia but has since welcomed many new members of both

For more on **member retention**, check out the article on page 21

genders who want to work towards better treatment options in your area, then it is probably a good idea to rethink the group's vision to be more inclusive. You may also want to rethink your group's vision in light of possible future needs and expectations, such as proposed changes to healthcare coverage policies that could affect treatment, or the professional development of your team members.

genders who want to work towards better treatment options in your area, then it is probably a good idea to rethink



### NEW VALUES

The foundational values of your team are less likely to change frequently, but you must remain open to the idea. You may wish to add to the group's stated values, or modify them to reflect the changing circumstances and profile of your team. For instance, reassessing your values to incorporate democratic principles, such as the equality of all members and fairness in the decision-making process, is highly valuable. New partnership opportunities might prompt you to set formal parameters for your group's relationships with sponsors. If the group decides to increase its online profile through social media tools, you may wish to establish guidelines around privacy and the sharing of information.

For more on **democracy**, check out the article on page 27

### NAVIGATING CHANGE TOGETHER

Whether it's setting new short or long-term goals, identifying a new vision, or re-evaluating the values of the group, every member must be welcome to participate in the discussions. The whole group needs to be on board and involved in this process, as the changes will affect them directly. It may be challenging to reach an agreement

For more on **effective communication**, check out the article on page 24

on changes in a group setting with diverse opinions. When individuals believe strongly in their idea, they will naturally defend it passionately. Through clear and open communication, within a team built on trust and respect, you will be able reach a conclusion that everyone can work with. Your shared vision of contributing positively to the bleeding disorders community will serve as a strong driver for collaboration and a foundation on which to build your team's various projects.

For more on **team work**, check out the article on page 9

When the core principles that define the group and the projects that you undertake appeal to the current membership, they will be far more likely to remain involved and to contribute their skills and energy, resulting in success for the youth group!

*Originally published online January 2016*

## SHOW OF HANDS

### USE THIS MULTIPLE CHOICE QUESTION TO START A CONVERSATION ABOUT EVOLVING WITH CHANGE

Ask your youth group which of the following they think would be the best reason for a youth group to set new goals. Invite them to explain their choice(s).

- A Because the previous goals have been achieved and the group needs new challenges
- B Because the previous goals were too ambitious and the group has lost motivation
- C Because your membership has changed, or there are new realities that the group is dealing with
- D Something totally different (ask them to describe)

## DIGGING DEEPER

### INVITE YOUR YOUTH GROUP MEMBERS TO EXPLORE THE THEMES OF THIS ARTICLE

Present the ideas in this article to your youth group, or invite them each to read it. Ask them whether they think the group's current goals are still appropriate. Are they challenging enough? If new goals would be appropriate, how might the group go about setting them?



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