

HEMOPHILIA ORGANIZATION DEVELOPMENT

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MEDIA RELATIONS

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Federación Española de Hemofilia

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Media Relations

David Silva

Introduction

All organizations, whether profit-driven or charitable, must learn how to effectively communicate who they are, their objectives, functions, and activities. Hemophilia and other inherited bleeding disorders organizations, by their very nature, may not have the resources to hire a communications professional or fund an ambitious communications and media strategy to help them do this. However, all such organizations, regardless of available resources, can benefit from forming a relationship with the local and perhaps even national media. This monograph is meant to serve as a practical guide to help hemophilia and other inherited bleeding disorders organizations create and maintain this mutually beneficial relationship.

Whether it is intended or not, the general public will form an opinion about an organization based on what it says or even what it does not say. An organization must therefore think about what it wants to communicate to the public and take the necessary steps to transmit that message effectively. Creating the right image for hemophilia and hemophilia organizations is crucial to being successful in influencing the healthcare policy debates in each country, in fundraising initiatives, and in communicating a positive image of people with hemophilia and other inherited bleeding disorders.

Some organizations have a communications plan: a document that maps out how the organization will share information related to its work with patients, the general public, government, healthcare providers, and other stakeholders. An effective communications plan addresses the following points:

- What is your organization's philosophy/mission?
- What kind of message do you wish to transmit?
- What limitations do you have?
- What actions can you take to achieve your communications goals while taking your limitations into account?

Using the media to communicate with the public is often part of the communications strategy. Even organizations that do not have a formal communications plan can benefit from building a relationship with the

media and from understanding the ways in which the media can help them meet their communications goals.

Types of Media

"Media" is a generic term that includes print media (newspapers and magazines) and electronic media (TV, radio, and the Internet).

Certain types of media will be more relevant for a particular story than others. For example, if the story has a particularly visible element, consider contacting the local TV station. Another story will be more appropriate for print media or Internet. By watching, reading, and listening to your local media, you will be able to identify the types of stories used by different print and electronic media outlets.

Do not underestimate the value of the regional press. Although its audience is usually smaller than that of national media outlets, its readers/viewers/listeners are particularly interested in what the press has to say about the area/region.

Print media

Print media is ideal for comprehensive, thought-provoking information and useful for conveying long-lasting information (i.e. things that will still be true in a week or two). Print media is most interested in research results, figures, statistics, explanations through interviews, testimonials, etc.

Newspapers

Newspapers can be daily, weekly, bi-weekly, monthly, etc. They can come in standard or tabloid size and reach a significant percentage of the reading public. Because of the broad demographic reach of most newspapers, it is difficult to target a specific audience. However, newspapers are effective in increasing awareness of the organization and its activities within a specific geographical area.

Magazines

Magazines are usually focused on a more specific target audience but they have a much longer lead time (many days and even weeks between the writing

and the publication of a story) so it is important to take into account the sort of news you are going to spread. Magazines are better suited for more in-depth coverage than newspapers.

Others

Other types of print media like flyers or brochures can either inform or educate a targeted group of people.

Electronic media

Electronic media is immediate so timing is critical and deadlines are even tighter. This type of media favours brief and specific stories and is ideal for transmitting impact information: overall data, specific figures, and brief testimonials.

Television

Television stations may be interested in stories that have a strong visual element, such as an event involving a local dignitary or the opening of a new treatment centre with high-tech equipment, etc. Television is one of the most popular and appealing media for these types of stories, but it can be expensive. Television commercials are costly to produce and air-time, even for a 15-second spot, is very expensive. There are other options to consider, though, including:

- **Public service announcements (PSAs):** In some countries, many television stations (both national networks and community stations) broadcast PSAs, but their requirements vary dramatically. Phone each station and ask about the formats and deadlines for PSAs. The PSA producer or public relations person will be able to help you. When writing a PSA, brevity is the goal. Stick to the facts and make sure you include the name and address of the organization as well as the person in charge of handling media relations.
- **News coverage:** Television news coverage can be difficult to obtain. Program directors, like editors, receive a huge number of news releases and requests for coverage, but a well-written press release (see page 5) will sometimes get their interest.
- **Local programs/interview shows:** These, rather than newscasts, may be the best option for hemophilia organizations. Talk shows and news-magazine shows cover a wide range of human interest stories. They use in-studio interviews as well as on-location shoots.

- **Community television programming:** Although the community television audience is smaller than that of a larger network, community TV is the best bet for in-depth television exposure.

Radio

Radio offers the public a fast, effortless way of getting information. It is a popular medium and one to take advantage of.

Local stations are often looking for local news. Radio provides numerous publicity opportunities: PSAs, newscasts, current affairs programs, interview programs, and open-line shows where listeners can call in and share information and opinions.

Internet

In today's electronic age, the internet — where it is available — is an increasingly important way to communicate with the public. It is often the first place people will look when searching for information about an issue or organization. Therefore, it is very important that hemophilia and other inherited bleeding disorders organizations maintain easy-to-navigate and updated websites about their organizations and work. In addition, the internet offers a variety of other tools that reach a broad and international audience, which should not be overlooked. These include online journals, publications, news-alerts, on-line press release services, blogs, and social media websites (such as Facebook or MySpace), amongst others.

Building Media Relations

Whenever possible, inform and update the media with interesting and positive stories. The media can enable the hemophilia and other inherited bleeding disorders community to communicate with a wide audience including potential funders, policy makers, and the general public. The image the public has of an organization is often shaped, at least in part, by the publicity provided by the media. Regular media coverage of hemophilia and other inherited bleeding disorders reiterates and enhances the organization's position as the lead spokesperson on hemophilia and related issues and creates an opportunity for people with bleeding disorders to position themselves as positive and active participants in the local community.

Hemophilia organizations can use the media proactively to help build their public image and reputation. Creating

positive dialogue about your organization through the media is a lot cheaper than advertising. The best strategy is to make the media your ally.

Build a list of media contacts

It is very important to have a database or other way to gather information on the journalists with whom you are creating professional relationships. These databases should include basic information such as the type of media they work in, the audience they reach, their contact information, etc. You can also add notes on the conversations or communications you have with them on an ongoing basis.

Pay attention to local and national media outlets (newspapers, magazines, television and radio stations, etc.). Take note of the correspondents, editors, and hosts who write or talk about health, news, and consumer issues. You can also call local media outlets to ask for these names. Identify the features editor of newspapers and/or magazines and the program directors, researchers, and hosts of local TV and radio networks.

The sales office of print publications can usually provide you with information on their circulation and readership profile. The circulation figure will tell you how many people you can expect to reach through the publication and help you decide whether it is worth spending any time on it. The readership profile will help you determine if a particular publication will allow you to reach your target audience effectively. TV and radio stations can usually provide similar information.

You should also phone all your local newspapers to find out when their copy deadlines are. Different newspaper departments have different deadlines and features editors usually need to submit stories well in advance (sometimes days ahead) of the publication date. Record all this information in your database as well.

Establish and maintain relationships

There is nothing “magic” about the media. They are a business like any other, with tight deadlines to respect, financial constraints, hierarchy, fierce competition, and a sophisticated audience.

Once you have identified key media contacts, contact the ones you are most likely to regularly inform about the organization’s activities. One way to get to know journalists is by taking them out for lunch. This is an opportunity to discuss where hemophilia

and other inherited bleeding disorders might fit in to their publication or future stories, but be extremely well prepared. Run through the possible questions you will be asked and think of the best ways to “sell” your story (see “Selling your story” on page 4).

It is essential to maintain cordial, productive, and ongoing relationships with journalists working in all types of media without discriminating against anyone based on their political ideology or bias. Make sure that your media contacts can depend on you to provide them with clear, timely, and accurate information about your organization and its activities. Doing so on a regular basis will help you establish a relationship of trust, which is in everyone’s best interest. The more relevant information there is on an organization and the clearer, faster, and more accurately that information is communicated, the better the results will be.

Look at establishing a relationship with the media as a goal in itself and not just as a means to an end. Journalists do not like to be “used” only when an organization needs them. They are much more likely to respond to requests if they know that you are always available to provide them with the information they need.

Even if they do not have a specific staff member dedicated to communications and media relations, all hemophilia and other inherited bleeding disorders organizations should:

- have a key contact person that can establish or already has established a relationship with the media, and that can provide accurate, quick, and honest information about hemophilia and other inherited bleeding disorders and about the organization in particular;
- designate a spokesperson who can answer questions from the media or participate in interviews;
- be prepared to handle requests for information through press releases, press conferences, interviews, articles, reports, etc.;
- understand the nature of media professionals’ work (short deadlines, need for reliable sources, etc.) and help make their job easier;
- avoid trying to buy a journalist’s professional judgment with any kind of incentive;
- invite the media to all events that may be of interest to them;
- thank and recognize media contacts when they help disseminate information about the organization or anything related to its cause.

Communicating with the Media

Media requests

Occasionally, a journalist may come knocking on your door asking for specific information for an article or special report. Hemophilia organizations that do not have a person dedicated exclusively to communications or media relations may find it difficult to supply the required information in a clear and timely fashion. To avoid this problem, hemophilia organizations should always have some basic information—statistics on the hemophilia and other inherited bleeding disorders population in their country or region, the main goals and challenges of the organization, its activities and services—already prepared. Having this information on hand, and having a person dedicated to acting as the organization’s spokesperson, can help provide the quick responses that journalists need. What journalists like most is to be provided with fast and accurate information, and the assurance that they can count on you in the future.

Selling your story

The best way to interest the media in your story is to make it “newsworthy”. News is any information that is interesting or unusual. The media are interested in local stories or national stories with a local angle. Before deciding to involve the media in a particular aspect of the organization’s work, ask yourself if the story:

- builds awareness of the organization, of the services it offers, and of the needs of its members;
- creates a need or increased desire to support the organization, its members, and the services it offers;
- has a local angle;
- passes the “interest test”. Ask yourself and your colleagues if the story qualifies as news to the media outlet you are targeting.

In order to get the media interested, you will need to “sell” your information to journalists so they can turn it into news. Some stories that the media are usually relatively willing to publish include:

- Opening of new facilities
- Signing of agreements
- National or local prizes
- Appointments of officers, special committees, etc.
- Assemblies, conventions, symposiums, events
- Anniversaries, World Hemophilia Day celebration, etc.
- Presentation of new projects or corporate reports
- Training activities

- The organization’s point of view on new laws or regulations
- Technical reports, bids, diagnoses
- Educational campaigns
- Presentation of studies, surveys, probes
- Tributes or awards to persons or institutions

Once you have identified a good story, you need to share it with the media in a way that will grab their attention. You must show journalists the importance, scope, and positive impact of the organization and the specific message you are sharing. Before making the first contact, evaluate what the media are interested in and what the best way of presenting the information will be. Express the information clearly, with excellent grammar, and correct spelling. Ask yourself:

1. What should be said?

Think carefully about the message that you want to send, starting from the premise that what might seem interesting to you may not be interesting to the audience you are going to address.

2. Who should say it?

Identify a spokesperson or spokespersons who will give the message a voice and a face. It is important to prepare this person well so he/she is clear on what should and should not be said and how it should be said.

3. Who do you want to reach?

The message should be addressed to those audiences you feel would be most interested or affected by what you have to say. Then adapt the language of your message to make sure that it is understandable to that audience.

4. Through what media?

Select the type of media that will best suit your message, intended recipients, and the response you expect (see “Types of Media” on page 1).

Media Relation Tools

There are many ways to present your information to the media. The choice depends on a combination of factors, including the nature of the information you want to transmit, your target audience, and the media you intend to use. The media relation tools that are most often used are explained in greater detail below.

Press releases

Press releases are the most common and among the easiest ways for organizations to get the information they feel is important to the media (see “Annex 1” on page 9).

Writing a press release

Before writing a press release, you have to be clear on what the news actually is. What is interesting to an organization may not be so interesting to the general public. You should also look at things from the audience’s perspective and make the information attractive by emphasizing something new or out of the ordinary. Using a real person with a name and face is a good way to make the information you are presenting meaningful to your audience. For example, if you want to inform the public that your organization is starting an educational project so children can learn self-treatment techniques, you may want to put a face to the project. Look for a volunteer who is involved in the project and will agree to tell his or her story to the media. The general public likes human interest stories and the media know this. Sometimes they themselves will ask for an interview with a person they can tell the story through. If you are already prepared for this, it will help get the journalist’s attention and make it easier for him/her to publish your message.

Once you have decided your story is news, you will need to write your press release. Gather the necessary facts and decide how to present them clearly and concisely. The press release must answer what are known as the five “Ws”:

- Who?
- What?
- When?
- Where?
- Why?

Sometimes, a sixth question can be added: How?

There are several elements to a successful press release:

Title/headline: Try to stick to the facts. It should be short and catchy to get the reader’s attention so he/she will keep on reading. It should express the essence of the story.

Date: Always put the date of issue (i.e. the day you send your press release to the media) in the top right corner of the first page. Put the date when the press release can be used (i.e. published) in the left

hand corner. In most cases, a press release can be used on the day of issue and should include the words “FOR IMMEDIATE RELEASE” in the left hand corner. The exception is if you want to send the information to the media in advance so the journalist can prepare and make arrangements to cover the story. In this case, you would write: “EMBARGO: NOT FOR PUBLICATION UNTIL [INSERT DATE AND TIME]”.

Lead: This is the first paragraph of the release. The lead serves to emphasize the most significant aspects of the news item (the “who” and “what”), which will then be developed in the body of the release. A good lead will grab the reader’s attention. This may be the only paragraph that a busy journalist has time to read.

Body of the news item: The body of the press release will answer all the other questions (the “how”, “when”, “where”, and “why”). Use short sentences and cut out any unnecessary adjectives. Try to aim for a maximum of 200-300 words for the entire press release. A journalist can always ask for more information if he/she is interested. If you want, you can also include background information on either the organization itself or on the specific project the release is about.

Contact name: At the end of the release, list the name, job title, business address, and telephone number of the person or persons issuing the release so that journalists can contact them for more information.

Tips for writing a press release

- Be specific and concise.
- Use short sentences.
- The title should tell the story in a nutshell, written in the present or future tense.
- Use active verbs.
- Do not use jargon or complex scientific language.
- Quotes give a press release life and make it more interesting.
- If possible, use a real person to make your story come alive to the reader.
- Check spelling and make sure facts are accurate.

Source: Effective Use of the Media, Irish Haemophilia Society

Distribution and follow-up

Once you have written and reviewed your press release, you will want to distribute it to all the appropriate media contacts.

- Send your release to actual people – not just titles. This means that your media list needs to be kept up to date.
- Provide the media with enough advance opportunity to use your release, particularly if it is announcing an event that has yet to happen.
- Make sure that the person listed as the contact at the end of the press release is available for follow-up calls. Respond promptly to inquiries – within the hour if at all possible. Get a knowledgeable backup person to respond to press inquiries if the primary contact person is called away.
- Distribute a general release to as many contacts as you can. Do not play favourites with the media – distribute your release so that everyone receives it at about the same time.
- If you have people who are available for interviews to support the story, say so. A “note to the editor” will do the job. Do not force the editors or reporters to guess.
- Do not lecture or blame reporters or editors for not running your story.
- If there is a substantial mistake in the way your story was reported, let the media know in a respectful and courteous manner.
- Understand what it means for you or other members of your organization to speak with the media, either on the phone or in person. Do not say anything “off the record” unless you have a very long-standing and trusting relationship with the reporter. If you do not want something reported, do not say it.
- ensure that all journalists who are attending the event know the date, time, and where to go. Provide a timetable of events for the visit so that they know what to expect and, if necessary, include maps that clearly illustrate the location;
- make sure that someone from the organization is available for an interview at the end of the press conference. If the event is to be attended by a radio or TV journalist, make sure a quiet room is available for conducting interviews;
- fully brief all members of the organization who will be present during the press conference;
- carefully plan who is going to speak and what each person is going to say during the press conference;
- prepare a report or press kit (see below) for each of the journalists that will be attending, which includes the information that was presented at the press conference, the speeches, statistics, and other data provided by the speakers. After the press conference is over, these can be sent out to journalists who did not attend;
- after the press conference is over (later in the day or a day or two later), follow up with the journalists who were there to make sure they have all the information they need and to politely ask if and how they are going to report on what was presented.

Press conferences

When information is especially innovative and important or it involves other institutions, you can call a press conference. For example, a hemophilia organization may want to call a press conference when a new hemophilia and other inherited bleeding disorders treatment centre is opened, modernized, or new equipment has been installed.

When planning a press conference or visit:

- send out a press announcement a week in advance informing journalists of the event. This is similar to a press release and should answer the “five Ws”. Inform the press if any VIPs or government officials will be attending;
- follow up the press announcement with a phone call two days before the event to see if the journalist will be attending;

Press kits

Press kits are informational packages that contain more information than a press release, which you can give to the media at a press conference or any other event.

A press kit should include precise data such as statistics, comparative graphs, photographs, etc. Information should be well-structured to capture the reader’s attention and it should be as visual as possible. Avoid long sentences and highly technical language as much as possible.

Hemophilia organizations can also prepare press kits with basic information about hemophilia and other inherited bleeding disorders, the number of patients diagnosed in the country or region, and the care those patients receive. This will help you be prepared to respond to media inquiries.

Interviews / panel discussions

Occasionally, a reporter may contact the hemophilia organization to comment on a story he/she is working on, or may request an interview in response to a press release you sent out or a conference you organized.

If you or any member of your organization is going to speak with the media, remember the following.

1. Be prepared!

Always plan what you want to say before you speak to a member of the media and make sure that your message fits in with your organization's point of view. Always check your facts before answering a journalist's question and make sure that the information you give can be substantiated by facts and figures.

2. Speak to your target audience.

Before the interview, decide who it is you need to get your message across to. Do you want to target women as part of an outreach activity? Are you seeking possible sponsors for a new project? Consider how they might respond to what you are talking about and tailor your message to them accordingly.

3. An interview is an opportunity to get your message across – make the most of it.

Approach the situation as an opportunity to share your positive message. Decide beforehand what key points you would like to discuss and make these points often during the conversation.

4. Stay in control.

As much as you can, try to maintain control over the direction in which the questions are going. Avoid distractions. Being well prepared will help you control nervousness during the interview.

5. Do not answer if you do not want to.

You have no obligation to answer a question. Your only obligation is to respond to it.

6. Relax at your peril.

Do not relax or joke unless you do not mind seeing what you say in print. Unless you have a long-standing and trusting relationship with a reporter, say nothing off the record.

7. Give them what they need.

Provide quotable phrases – that is what reporters and TV and radio hosts are looking for.

8. Practice what you will say.

Ask someone to help you practice for the interview. Think of the questions you are likely to be asked and rehearse your answers out loud. In some

instances, the interviewer may be willing to share the questions he/she will ask you beforehand, but be prepared for surprises.

Articles and reports

Given the large number of corporate or organizational publications that exist, you may have an opportunity to include an article or report in a magazine, in the newsletter of another organization similar to yours, or in the newsletter of a company that has already collaborated on your projects. In the hemophilia and other inherited bleeding disorders community we find several examples of this: many patient organizations have their own publication and separate publications may be produced by the hospital or hemophilia treatment centre where care is given, by the university to which the centre is affiliated, and by umbrella organizations in individual countries. The WFH also has several publications, including *Hemophilia World*.

It is important to pay attention to publications of this kind because you never know what opportunities can come up for your organization.

Whenever possible, contact the people responsible for these publications to offer them pre-prepared materials (articles, news reports) or to ask whether they would be interested in writing something about your organization.

Newsletters

Newsletters are useful to keep the organization's internal and external audiences informed at the same time. They are very useful public relations tools for communicating corporate culture and involving your stakeholders in the organization's mission. A newsletter is not the ideal tool to communicate with the media. However, you may use articles from your newsletter as a source for potential news stories that can be rewritten and circulated as press releases. You may also send a copy of your newsletter to a journalist who has requested background information about your organization. It is usually not a good idea, though, to routinely send a copy of your newsletter to your media contacts. Most would find it much too long to read and simply discard it.

Website

A website can have many uses. Its principle use is as an institutional site where anyone can learn about the organization and its mission. It can also be used:

- to attract donations and sponsorships or to recognize existing donors;
- to attract volunteers and collaborators;
- to establish and/or improve the reputation and the image of the organization;
- to provide certain services to the organization's stakeholders;
- to sensitize and educate the public, particularly the more media-savvy youth;
- to report to and mobilize the organization's members.

It is important to define the purpose of the organization's website. If the site's primary function is not clearly defined, it can turn into a place with too much information where one gets lost easily.

In order for the website to be useful to the public, its content must be current, relevant, concise, and useful for the target audience. Appropriate content may include:

- Information on the benefits of membership and a membership application form
- A description of the organization's projects and/or services
- Answers to frequently asked questions
- Statistics
- Press releases and opinion articles
- Subscription to a news service
- Submission of online queries

Nowadays, it is fundamental for hemophilia organizations to take advantage of their websites to interact with members and other stakeholders. To do so, the websites can incorporate elements such as:

- Discussion forums/chat rooms
- Surveys
- Suggestion boxes
- Educational games (for example, a questionnaire that tests the user's knowledge about hemophilia)
- Forms (donation, subscription, etc.)
- Blogs
- Electronic publications


Electronic publications are relatively cheap to produce. In some instances, using the website to produce and distribute a publication can be a good way to save time and money. The most common is the electronic newsletter, which allows the organization to spread word of its activities and most relevant news.

Newsletters, brochures, and other direct marketing pieces have traditionally been sent via mail (post). Nowadays, e-mail all but eliminates mailing costs, though one must still be careful that e-mails do not end up in people's junk folder and/or remain unread. Also, not all of an organization's constituency may be comfortable using e-mail as yet.

A discussion forum is an ideal vehicle to stimulate debate and participation. The ideal user will think of it as a place to formulate ideas and share experiences. In the case of hemophilia organizations, it can be a means of bringing doctors and patients together – a place where patients can raise concerns and questions about their diseases in general or about their individual experiences.

Conclusion

Building and maintaining a relationship with the media is a good way for hemophilia organizations to increase awareness of bleeding disorders and to publicize their programs. Regular media coverage will position the organization as a key authority on hemophilia and will allow you to communicate positive and interesting stories to a wide audience.

The media can be a powerful ally. Cultivating and maintaining a personal relationship with key media contacts in the country or region can go a long way in helping hemophilia organizations achieve their goals. 

Annex 1: Template Press Release



[Insert: "FOR IMMEDIATE RELEASE"
or "EMBARGO: NOT FOR PUBLICATION
UNTIL (Insert Date and Time)"]

April 15, 2009

NEWS RELEASE

Standing together to improve hemophilia treatment

World Hemophilia Day brings together the global bleeding disorders community

(Montreal, April 15, 2009): Behind every person with hemophilia is a much needed team of support. This April 17 marks the 20th anniversary of World Hemophilia Day where hemophilia organizations around the world increase awareness of hemophilia and other bleeding disorders.

This year's World Hemophilia Day campaign, "Together, We Care", focuses on the importance of comprehensive care, which is central to treating the physical, emotional, psychological, social, and educational needs of people with hemophilia and other bleeding disorders. This is best done through a multidisciplinary approach where all key healthcare professionals come together in specialized care teams to look after all the treatment requirements of the patient.

Involving a specialized comprehensive care team in hemophilia care ensures:

- Accurate diagnosis
- Prompt and effective treatment
- Fewer hospitalizations
- Healthy joints and muscles
- Support for families

On April 17, World Hemophilia Day, the World Federation of Hemophilia (WFH) is launching a video podcast titled "Together, We Care: A Comprehensive Approach to Bleeding Disorders" at www.wfh.org/whd. This video podcast, made possible with funding from Baxter Healthcare Corporation, highlights the impact and benefits of comprehensive care.

Comprehensive care is important for patients with bleeding disorders in both developing and developed countries. "It may not exist in developing countries and may be threatened in developed countries by government budget cuts and other measures affecting the delivery of healthcare," said Mark Skinner, WFH president. "Our vision of Treatment for All means more than just treatment products. It also means diagnosis, care and treatment by a multidisciplinary team of trained health care specialists."

Visit www.wfh.org for more information about World Hemophilia Day. The World Hemophilia Day website is supported by Bayer and Baxter.

The "Together, We Care" campaign is part of the WFH's continuing efforts to improve care for people with inherited bleeding disorders around the world.

About hemophilia and other bleeding disorders

One in 5,000 boys is born with hemophilia. This means that their blood does not clot properly and this can often be fatal due to internal bleeding. However, with proper care and management, patients with hemophilia and bleeding disorders can lead a longer, healthier life.

Hemophilia, von Willebrand disease, and other factor deficiencies are lifelong bleeding disorders that prevent blood from clotting properly. People with bleeding disorders do not have enough of a particular clotting factor, a protein in blood that controls bleeding, or it does not work properly. The severity of a person's bleeding disorder usually depends on the amount of clotting factor that is missing or not working. People with hemophilia can experience uncontrolled internal bleeding that can result from a seemingly minor injury. Bleeding into joints and muscles causes severe pain and disability. Bleeding into major organs, such as the brain, can cause death.

About the World Federation of Hemophilia (WFH)

The World Federation of Hemophilia (WFH) is an international not-for-profit organization dedicated to improving the lives of people with hemophilia and related bleeding disorders. Established in 1963, it is a global network of patient organizations in 113 countries and has official recognition from the World Health Organization. Visit WFH online at www.wfh.org.

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