



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

About Project Red Flag and Woman-To-Woman

Welcome and thank you for volunteering for the Woman-to-Woman program.

Project Red Flag: Real Talk About Women's Bleeding Disorders is the National Hemophilia Foundation's (NHF) public awareness campaign to reach more than two and a half million women nationwide with undiagnosed bleeding disorders. The campaign will educate women and their healthcare providers about the symptoms of bleeding disorders, especially von Willebrand disease (VWD), and encourage proper diagnosis and treatment. Project Red Flag materials have been designed to help chapters, associations, hemophilia treatment centers (HTCs) and consumers raise awareness of women's bleeding disorders in their local communities.

The Woman-to-Woman curriculum is just one of the many resources that NHF has developed as part of the Project Red Flag (PRF) campaign. The Woman-to-Woman project is designed to prepare volunteers to go out into the community to:

- teach women about the signs and symptoms of bleeding disorders,
- identify undiagnosed women, and
- connect these women with hemophilia treatment centers, chapters/associations and other resources.

Woman-to-Woman volunteers are able to:

- make the issue of bleeding disorders more realistic and interesting for the listener by sharing personal stories
- elicit questions from listeners that the listener may have been unwilling to share before, and
- identify groups not accessible to the chapter/association or hemophilia treatment center.

NHF has also created the Project Red Flag Toolkit. Note that the slides for conducting the Woman-to-Woman presentations are available in this toolkit. You may also download the PowerPoint slides along with the Woman-To-Woman curriculum in its entirety from the Project Red Flag Web site at www.projectredflag.org. The toolkit contains slide presentations for providers and useful brochures as well. To learn more about the Project Red Flag campaign or to obtain any materials, please contact NHF Project Red Flag Coordinator, Anna DeSimone at (800) 42-HANDI ext. 3705 or adesimone@hemophilia.org.

Your assistance in this program is not only appreciated but also necessary for its success. You will be making a difference in the lives of women who may be suffering from an untreated bleeding disorder.



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

How to Use The Volunteer Manual

The format of the Woman-to-Woman Volunteer manual has been designed to encourage consistency in training procedures that will ensure the success of the program. The Woman-to-Woman Volunteer Manual is divided into two columns.

The right hand column contains the content of the Woman-to-Woman training sessions. This information is almost identical to the information in the Trainer Manual. It is a point-by-point description of what items will be covered during the training session(s). The left hand column contains space for the volunteers to take notes during the training sessions and while preparing for their presentations.

Each training session will take approximately one hour and 30 minutes to complete.

The National Hemophilia Foundation's Project Red Flag Toolkit is referenced in the manual and is used as a visual aid throughout the training. This toolkit contains useful slides, speakers notes and brochures for the small and large group presentations. Volunteers will need access to the slides and speaker's notes. You can obtain these materials from your trainer.

Your trainer will provide you with additional handouts during the training sessions. Handouts will include forms, visual aides and supplemental materials.



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

TABLE OF CONTENTS

Session One.....1

Part One: Introduction and Project Discussion

- Welcome /Introduction of Trainers
- About the Project Red Flag Campaign
- Description of Project
- Timeline
- Housekeeping Issues
- Confidentiality
- Pre-training Assessment
- Introduction of Volunteers
- Description of the Problem

Part Two: Medical Information

- Building Blocks to Identification and Treatment
- Normal Blood Clotting Mechanism vs. a Bleeding Disorder
- Signs and Symptoms of Bleeding Disorders in Women
- Types of Bleeding Disorders in Women
- Diagnosis of Bleeding Disorders
- Treatment of Bleeding Disorders
- Genetics
- Community Resources
- Summary
- Homework Assignment
- Networking

Session Two.....20

Part One: Techniques for Public Speaking

- Introduction
- How to Convey the Message
- Effective Presentation Skills
- Setting Personal Boundaries



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

TABLE OF CONTENTS (Cont'd)

Part Two: Conducting the Presentations

Networking Skills

Materials Needed

Steps to Conducting the Presentation

Special Considerations

Group Exercise: Personal Narrative

Practice Presentation Sign Up

Summary

Session Three..... 32

Practice and Feedback

Introduction

Presentation Ground Rules

Practice Presentation(s)

Presentation Feedback

Small Group Presentations

Woman-to-Woman Timeline and Checklist

Post-Training Assessment

Summary

Session Four.....39

Part One: Volunteer Networking

Welcome and Introductions

Volunteer Networking

Part Two A: New Volunteers

Part Two B: Returning Volunteers

Debriefing the Presentations

Discussion of Large Group Presentations

Group Leaders

Summary

Closing



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

I) SESSION ONE

SESSION ONE OBJECTIVES

- Understand the need for an outreach program to women.
- Learn about the Project Red Flag campaign.
- Understand the prevalence of bleeding disorders in the United States and in the state in which the training is taking place.
- Understand the normal blood clotting process.
- Understand why blood does not clot properly in a person with a bleeding disorder.
- Identify the signs and symptoms of a bleeding disorder.
- Identify the more common bleeding disorders in women.
- Describe how bleeding disorders are diagnosed.
- Describe appropriate treatment for bleeding disorders.
- Understand the genetic component of bleeding disorders.
- Identify community resources.

SESSION ONE/PART ONE - INTRODUCTION AND PROJECT DISCUSSION

WELCOME/INTRODUCTION OF TRAINERS

Please write the name and phone number of the





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

contact person in your manual. This is the person who you will call if you have questions about the project.

Contact Person: _____

Phone Number: _____

Other important information:

- **Restrooms**
- **Breaks:** Planned breaks may be scheduled. If there are not any planned breaks you may feel free to get up and use the restrooms as needed.
- **Promptness:** Every session is important, timeliness is appreciated.
- **Contact Person:** Explain how and when the volunteers should contact him/her.
- **Sign-In Sheet:** Make sure that every volunteer signs the sign-in sheet. This attendance sheet will be present at all sessions.

DESCRIPTION OF THE PROJECT

The Woman-to-Woman project is designed to prepare volunteers to go out into the community to:

- teach women about the signs and symptoms of bleeding disorders,
- identify undiagnosed women and
- connect these women with treatment centers, chapters/associations and other resources.

Woman-to-Woman volunteers are able to:

- make the issue of bleeding disorders more realis-





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

tic and interesting for the listener by sharing personal stories

- elicit questions that the listener may have been unwilling to share before and
- identify groups not accessible to the chapter/association or treatment center.

ABOUT THE PROJECT RED FLAG CAMPAIGN

Project Red Flag: Real Talk About Women's Bleeding Disorders is the National Hemophilia Foundation's (NHF) public awareness campaign to reach the more than two and a half million women nationwide with undiagnosed bleeding disorders. The campaign will educate women and their healthcare providers about the symptoms of bleeding disorders, especially von Willebrand disease (VWD), and encourage proper diagnosis and treatment.

The Woman-to-Woman curriculum is just one of the many resources that NHF has developed as part of the Project Red Flag (PRF) campaign. PRF materials have been designed to help chapters, associations, hemophilia treatment centers and consumers raise awareness of women's bleeding disorders in their local communities.

NHF has also created a PRF Toolkit that includes brochures, media relations materials and general audience and provider presentations. To learn more about the PRF campaign or to obtain any materials, you can contact HANDI, NHF's information service at (800) 42-HANDI or handi@hemophilia.org. You may also visit the PRF Web site at www.projectred-flag.org.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

TIMELINE

Overview of sessions:

There will be four training sessions including this session.

Session 1 will focus on orientation to the program and medical information.

Session 2 will focus on public speaking techniques.

Session 3 will primarily be a practice session.

Volunteers will model a presentation.

Session 4 will focus on two issues.

First, the group will talk about the challenges and successes of the presentations. This discussion will help volunteers prepare for the large group presentations, for which they will sign up at this time.

Second, this session will include new volunteers and will be their orientation to the program and to the medical information.

HOUSEKEEPING ISSUES

Missed Sessions: Volunteers must attend all sessions before conducting presentations. In the event a session is missed, volunteers should call the contact person immediately.

Other ground rules:

- Stay on the topic.
- Only one person should speak at a time.
- Give positive feedback.
- Respect others.



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

CONFIDENTIALITY

The right of confidentiality is guaranteed under state and federal confidentiality laws for medical information shared with others in situations such as those associated with the Woman-to-Woman project. Confidentiality will be observed in the following situations:

In the **training:**

- It is important that the volunteers feel comfortable sharing information so that they can formulate their presentations to include their personal stories.
- Please do not discuss any personal information about your peers that you learn during the training. You also must not discuss personal information that you learn with HTC or homecare staff.

In the **presentations:**

- Volunteers may learn personal information about the listeners. Though the idea is to direct these listeners to care, the volunteer should not do this by directly telling medical staff about the specific circumstances.
- Volunteers should take care not to discuss personal information about others with close family members or friends. Since the presentations will be done locally, there is a likelihood that the person being spoken about could be identified as a member of the volunteer's community.

The rule of confidentiality is in place to protect all parties involved. Due to the fact that some of the





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

symptoms of bleeding disorders in women are of a very personal nature, adhering to the confidentiality rule is of utmost importance.

Your trainer(s) will provide you with an agreement to sign.

PRE-TRAINING ASSESSMENT

Purpose:

The assessments have been created to measure the volunteers' understanding of bleeding disorders. A post-training assessment will then measure the volunteers' knowledge of bleeding disorders after the training sessions.

Please note that individual scores will be measured in order to determine a volunteer's readiness for the community presentations. If a volunteer does not get 100% of the answers correct on the post-training assessment, she will have a private meeting with the trainer to discuss the questions she missed. The scores will also be used to compare the group's knowledge before and after the training to determine the impact of the training sessions.

INTRODUCTIONS OF VOLUNTEERS

Take a minute to think of two to three sentences about yourself that you would like to share with the group.

Include:

- Name





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- Bleeding disorder
- Why are you volunteering?

DESCRIPTION OF THE PROBLEM

Prevalence of bleeding disorders in women:

- It is believed that 1 to 2% of the general population in the United States has von Willebrand disease.
- This means in our state _____ women potentially have von Willebrand disease.
- Of these, only ____ are being seen at treatment centers around the state.
- Twenty percent of women with heavy menstrual periods may have an underlying bleeding disorder such as von Willebrand disease.

Other bleeding disorders in women:

- Platelet function defect
- Hemophilia (often as carriers)

Potential physical consequences of an untreated bleeding disorder:

- Excessive bleeding and pain that limit physical activities and reduce quality of life
- Unnecessary surgeries, particularly hysterectomies
- Problems during the birthing process





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Potential psychological consequences of an untreated bleeding disorder:

- loss of dignity and control
- inhibited sexual contact
- isolation

SESSION ONE/PART TWO - MEDICAL INFORMATION

The following is a presentation of the building blocks to understanding bleeding disorders.

Refer to the illustration in Appendix O: Building Blocks to Identification and Treatment of Bleeding Disorders for a specific outline of the topics that will be addressed.

Also, please refer to Appendix B: Medical Information Worksheet. This appendix may be a helpful tool in creating a master sheet of medical information for you. You can use this sheet to take diagnosis-specific notes during the training.

NORMAL BLOOD CLOTTING MECHANISM VS. A BLEEDING DISORDER

- A bleeding disorder is a flaw in the body's blood clotting system.
- von Willebrand factor, like factor VIII and IX (called hemophilia A and B respectively) are proteins in the blood.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- Blood clotting (also known as coagulation) is the process that controls bleeding by changing blood from a liquid to solid state.
- When there is a defect or deficiency in a clotting factor or platelet, the clot is incomplete and bleeding continues. As a result, people with bleeding disorders bleed for longer periods of time.
- Someone affected by von Willebrand disease or a platelet function defect does not have the ability to form the platelet plug.

The Process of Blood Clotting

Normal Clotting:

1. Bleeding starts
2. Vessels constrict
3. Platelet plug
4. Fibrin clot

Abnormal Clotting:

1. Bleeding starts
2. Vessels constrict
3. Incomplete platelet plug, continued bleeding
4. Incomplete and/or delayed formation of fibrin clot, continued bleeding

SIGNS AND SYMPTOMS OF BLEEDING DISORDERS IN WOMEN

Depending on the level of normal clotting factor, a bleeding disorder may be considered mild, moder-





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

ate or severe. Bleeding symptoms vary depending on severity. Symptoms may vary between family members. Bleeding symptoms may also change over a lifetime. Stress, exercise, medicines and changing hormone levels during menstruation and during and after pregnancy may affect bleeding patterns.

Heavy or Prolonged Menstrual Bleeding:

- periods that last longer than 1 week,
- cause you to change a tampon or pad every one to two hours during the first day of your period, or use more than 2 dozen tampons or pads in one month, and/or
- cause you loss of time from school/work.

Easy Bruising:

- a bruise that is two inches or larger,
- occurs in more than one part of the body and/or
- has hard, tender bumps.

Lengthy or Frequent Nosebleeds:

- nosebleeds that occur more than once a year and are difficult to control, and/or
- take more than 10 minutes to stop, even with pressure.

Prolonged or Unusual Bleeding after Injury, Surgery, Childbirth or Dental Work:

- bleeding that has caused a doctor to note that you bleed more than expected or
- required blood transfusions.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Unusual Mouth or Gum Bleeding:

- mouth bleeding that occurs without injury or that lasts longer than four to six hours with injury.
- Gum bleeding when brushing teeth or
- Bleeding/oozing as teeth erupt.

TYPES OF BLEEDING DISORDERS IN WOMEN

von Willebrand Disease:

- General

Not everyone who has von Willebrand disease is symptomatic. For those who are symptomatic, typical signs include nosebleeds, easy bruising, heavy menstrual flow, and excessive or unusual bleeding from the mouth or gums.

Gastrointestinal or urinary tract bleeding may also occur.

Many people with von Willebrand disease may bleed heavily or for a longer time after surgery or injury than is usual.

Sometimes bleeding is caused by trauma, and at other times there is no known cause.

- Incidence
Affects 1-2% of the population.

Up to two and a half million American women may have a bleeding disorder, the most predominantly being von Willebrand disease.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Every year 30,000 women in the US have a hysterectomy due to heavy bleeding, and a significant number of these women may have a bleeding disorder that could be controlled without surgery.

One in four females with anemia may have an undiagnosed bleeding disorder.

Carriers of Hemophilia

- **General**
Female carriers of the hemophilia gene may have bleeding symptoms.

Carriers who exhibit symptoms are known as symptomatic carriers.

Carriers may suffer excessive menstrual bleeding, bruising, nosebleeds and bleeding following surgery, dental work or childbirth.

Some carriers may also have joint and/or muscle bleeds.

- **Incidence**
Over 30% of carriers have below normal factor levels.

25-30% of carriers report abnormal bleeding.

Platelet Function Defect





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- **General**
A defect in the platelets necessary for blood clotting is known as platelet function defect.

The symptoms associated with platelet function defects are very similar to those associated with von Willebrand disease.
- **Incidence**
Little information is available about platelet function defects, but the reality of the disorder is increasing.

DIAGNOSIS OF BLEEDING DISORDERS

If someone thinks they might have a bleeding disorder, they should:

- Talk to their primary care physician about their concerns.
- Rule out other disorders/diseases with the physician.
- Seek a referral to a local hematologist associated with the federally funded hemophilia treatment center network.

The following are the steps taken to diagnose a bleeding disorder:

- Personal history
- Family history
- Physical examination
- Specialized laboratory testing





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- Expert interpretation by a hematologist specializing in coagulation disorders

TREATMENT OF BLEEDING DISORDERS

The Influence of Diagnosis on Treatment

- There are a variety of treatments for bleeding disorders based on the type of bleeding disorder and the patient.

A von Willebrand disease type 1 diagnosis indicates an individual has a decreased amount of von Willebrand factor, but the von Willebrand factor function is normal.

A von Willebrand disease type 2 diagnosis indicates an individual has abnormal von Willebrand factor. Individuals with a type 2 diagnosis may also have a decreased amount of factor.

A von Willebrand disease type 3 diagnosis indicates an individual has total or near total absence of von Willebrand factor.

- It's important to note that individuals may have severe bleeding symptoms no matter what type of von Willebrand disease affects them.

Treatment

- There are a variety of treatment options available for von Willebrand disease. Some of the most commonly used medications for the treatment of





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

von Willebrand disease include:

Hormones: treatment with estrogen and progesterone, the hormones found in oral contraceptives, can raise the levels of factor VIII and von Willebrand factor. This therapy can be useful for managing heavy menstrual flow and other bleeding. For women with type 1 von Willebrand disease, treatment with oral contraceptives may be an effective option. However for those who for any reason cannot take oral contraceptives, other options such as Amicar or tranexamic acid may be considered.

DDAVP: (desmopressin acetate) is a synthetic hormone. It works by causing the body to release von Willebrand factor and factor VIII. DDAVP is administered in several ways: intravenous, injected under the skin, or through a nasal spray. The nasal spray that is used to treat bleeding disorders is called Stimate and is different in strength from the DDAVP given to treat bed-wetting. People affected by type 1 and 2a von Willebrand disease, mild platelet function defect and symptomatic hemophilia A carriers typically use this source of treatment.

Factor VIII Concentrates Containing von Willebrand Factor: some types of factor VIII concentrates are rich in von Willebrand factor. Humate-P is a well-known factor VIII concentrate product licensed to treat von Willebrand disease in the US. There is another product used in the US called Alphanate that is licensed in Europe for VWD and is available but not yet





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

licensed for VWD in the US. These products are derived from pooled human plasma and are virally inactivated and considered pathogen safe. Factor VIII concentrates are infused into the blood stream. Individuals with von Willebrand disease undergoing major surgery are often administered these products. Although these products can be used for all types of von Willebrand disease, individuals affected by type 2 and 3 von Willebrand disease are generally the patients prescribed such a treatment. Patients with severe platelet function defects may need to receive transfusions of normal platelets.

Antifibrinolytics: these agents prevent clot breakdown and hence make the clot more firm or stronger. They are available in a tablet, liquid and an intravenous form. Two such agents are commonly used. 1) Amicar or epsilon aminocaproic acid that is available in the USA and 2) Tranexamic Acid: a treatment that is prevalent in European countries and is currently under consideration for licensing in the US. These agents are commonly used for mouth bleeding and bleeding from gums; the oral solution can be swished in the mouth. They are also given for bleeding from the intestines (gastrointestinal bleeding) that may manifest as vomiting blood or passing blood or dark (black) colored bowel movements. Low doses of antifibrinolytics are sometimes given to decrease heavy menstrual bleeding.

Localized Treatments: bleeding into the mouth or nose may be controlled with medication





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

applied at the bleeding site. A number of such agents are available as over-the-counter medicine. Surgeons sometimes use other types of local agents to decrease or prevent blood loss from the site of surgery.

Note for additional information, please review NHF's Medical and Scientific Advisory Council (MASAC) recommendations. These are listed on www.hemophilia.org. You can also contact HANDI at (800) 42-HANDI or handi@hemophilia.org.

Prevention

- Prevention measures (for example, no heavy contact sports, pre-treatment prior to an invasive procedure such as surgery or dental extractions, and wearing bicycle helmets).

GENETICS

- A hereditary disease is one that can be passed down through families or inherited.
- Inherited bleeding disorders are caused by defects in the genes (units of inherited information) that make the clotting factors needed for blood clotting.
- The abnormal gene in von Willebrand disease is on one of the regular chromosomes, not on one of the sex chromosomes as in hemophilia. Therefore, unlike hemophilia, which usually affects males, von Willebrand disease affects males and females in equal numbers.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- These genes, like all genes contained in cells, are passed from parents to children. Just as a parent may pass a physical trait such as a button nose to a child, a parent may pass the gene that results in a bleeding disorder.
- von Willebrand disease is a dominant trait. A parent who has von Willebrand disease has a 50% chance of passing it on to their children.
- A bleeding disorder can also be the result of a new or spontaneous mutation (change in the gene).

COMMUNITY RESOURCES

Local Chapter/Association:

Local Treatment Center Network:

National Organization:

NHF has many resources available as part of its





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Project Red Flag campaign:

National Hemophilia Foundation
Project Red Flag
116 West 32nd Street, 11th Floor
New York, NY 10001
<http://www.projectredflag.org>
Phone: 800-42-HANDI
HANDI fax: 212-328-3799
handi@hemophilia.org

SUMMARY

Main Ideas:

Next Meeting

Date: _____

Time: _____

Location: _____

HOMEWORK ASSIGNMENT

Personal narratives: using the Personal Narrative Guidelines handout, each volunteer should develop a narrative describing why they decided to become a part of this project. This narrative will be used during their presentations in the community.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

NETWORKING

Take time to meet the women who will be working on the project. This is an invaluable opportunity to meet other women who have shared similar experiences. Sharing ideas will also help the volunteers reach their personal goals with regard to spreading the message that Women Can Have Bleeding Disorders in their community.

II) SESSION TWO

SESSION TWO OBJECTIVES

- Learn how to set personal boundaries.
- Become familiar with public speaking techniques.
- Understand the information to be presented.
- Understand the most effective way to present the bleeding disorder information.
- Learn the skill of networking.
- Identify potential groups for future presentations.
- Become comfortable in sharing personal narratives with a group.
- Begin to develop a comfort level with presenting in front of groups.

SESSION TWO/ PART ONE - TECHNIQUES FOR PUBLIC SPEAKING

INTRODUCTION





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Session two will focus on three topics:

- How can you effectively convey your message?
- What is the content of your message?
- Where are you going to present your message?

HOW TO CONVEY THE MESSAGE

The volunteers will be speaking to both small and large groups. Though these two environments can feel very different as a speaker, the following are guidelines that generally apply to any arena.

Experiences with Public Speaking

Anxiety: People who are speaking in public are often troubled by anxiety. Some ways to alleviate anxiety are:

- Practice the presentation.
- Breathe deeply before presenting.
- Do the presentation sitting down (in small groups) or behind a podium.
- Think of the nervous energy as just energy and use it to add enthusiasm to the presentation.

EFFECTIVE PRESENTATION SKILLS

Do:

- Make eye contact - When speaking, try to make eye contact with each member of the group.
- Smile
- Be aware of posture - Stand or sit with a confident upright posture. Engage your audience





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

with your posture. Lean in towards them to invite comment and to create a connection.

- Speak slowly - It often helps to write "slow down" on your notes to remind you to speak more slowly. Sometimes you don't even realize how quickly you are speaking and you may lose the audience. Pause between important points.
- Speak loudly - Present the information in a tone of voice that is comfortable to listen to and is clear.
- Use visual aids - Presentations are always more interesting if the speaker has something for the audience to view. Slides will be provided for Woman-to-Woman presentations.
- Allow time for questions

Don't:

- Fidget - Rocking back and forth on your feet, handling objects, etc. may be distracting to an audience. Sitting or standing behind a podium can eliminate the anxiety causing this distraction.
- Look down - Be sure to make eye contact with the audience members to engage them in the presentation. When using notes, periodically look away from the outline or notecards.
- "Um" - Anxiety can also cause people to say "um" after every couple of words. This is distracting to the audience. Rehearse your presentations to increase your confidence with its message.
- Go off on a tangent - Telling your personal story and answering questions can cause the presentation to stray from the topic at hand. Remember





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

the time limitations and personal boundaries set prior to the presentation. Woman Can Have Bleeding Disorders is your message.

- Feel like you need all of the answers - There is nothing wrong with saying "I don't know, but I can find out for you."

Extras: The following are ideas to make the presentation more enjoyable for both the presenter and the audience.

- Greet each member of your audience as they arrive. In a large group, you may want to greet them at the door or mingle through the crowd to greet them once they are in the room.
- If it seems appropriate, sit down to present. This will make the presentation more informal.
- Memorizing the key points of the presentation can prevent many of the "don'ts" listed above.

SETTING PERSONAL BOUNDARIES

During and after the presentation members of the audience may ask questions. It is important for the volunteers to recognize their own level of comfort in particular situations. Setting boundaries may help them set limits and protect their privacy.

Setting personal boundaries in the following areas may be helpful.

- **Time:** time will be limited so it may not be possible to have a long conversation with any one audience member.
- **Emotions:** be aware of the amount of emotional energy necessary to conduct presentations and





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

hold conversations with audience members.

- **Personal information:** personal narratives will be shared with the audience. Set limits on the amount of information shared.

In order to maintain these personal boundaries:

- **Do not** give out home phone numbers or an address.
- **Do not** attempt to answer medical questions. Always refer the woman to her primary care physician or the chapter for a referral to a local treatment center.
- **Do not** counsel women in the audience. Listening to an individual's story without handling the problem is appropriate. Refer a woman who suspects she has a bleeding disorder to the local treatment center or chapter. This information should be listed on the brochure distributed to audience members. The goals of the Woman-to-Woman project are outreach, awareness and referrals for diagnosis and treatment.

SESSION II/PART TWO - CONDUCTING THE PRESENTATION:

NETWORKING SKILLS

The first step in getting the message out to the community is to identify organizations through which volunteers can present the information. To accomplish this, networking skills are necessary.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Personal Contacts

The best place to start is with community groups to which the volunteers belong. First identify the appropriate contact person. Then approach the contact person with the desire to do a presentation.

The project contact person can also send a letter to this person explaining the Woman-to-Woman project.

If the volunteers do not belong to any groups, they can begin by doing the presentation for friends and family.

Community Contacts

Friends and family members may also know of groups through which volunteers can conduct presentations.

If volunteers are unaware of the name of the contact person, they can get this information by contacting the organization directly.

Local newspapers can also be great resources. Community events and volunteer opportunities may be posted listing the names and phone numbers for local organizations and groups. The library may also be a resource for identifying community organizations and groups.

Making the Initial Contact

It may be intimidating to call someone unfamiliar.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

As mentioned, an introductory letter can be sent by the project contact person to initiate contact with the organization. Follow-up telephone calls can then be made to the contact person. It may help to rehearse the message before the volunteer calls or meets with a contact person.

Be clear and concise in the description of the project and the presentation. Volunteers can use the information provided in "Session One: Description of the Project" as a guide.

MATERIALS NEEDED

For small group presentations these materials are optional. ()*

1. Volunteer Manual
2. Slides*--slides can be used from the "Women Can Have Bleeding Disorders" presentation located in the Project Red Flag Toolkit. Note that there are 35mm slides or PowerPoint slides (photocopies of the slides can be used as handouts)
3. Slide projector* or laptop*
4. Screen*
5. Sign-up sheet
6. Brochures--can be used from the Project Red Flag Toolkit. Note that brochures are available in English and Spanish
 - a. "Heavy Periods"
 - b. "Facts You Should Know"
 - c. "For You and Your Doctor"
 - d. "Tips for Living"
7. Project Red Flag Web site (www.projectredflag.org)
8. Coffee, tea, water and a snack*





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

STEPS FOR CONDUCTING THE PRESENTATION

The presentation should be conducted in the following order to make a positive and strong impression on the audience.

Steps

1. Ask the women to sign in as they enter the room for the presentation. Explain that providing their address, phone number and e-mail is optional.

2. Welcome and Introduction

Introduce yourself.

Explain that you are working with the (chapter/association/treatment center name) to increase awareness about women and bleeding disorders.

Explain that the sign-up sheet will only be used to determine attendance. Names, addresses and phone numbers will be kept confidential. They will only be contacted if they ask for additional information following the presentation.

3. Housekeeping Issues

The presentation will last approximately one hour. This will include time for questions.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Please feel free to tend to your personal needs during the presentation.

There will be time for questions at the end of the presentation.

Please respect one another and hold what is said during this presentation to the strictest of confidentiality.

4. Describe the outline of the presentation.

"Today I'll be discussing the symptoms, diagnosis and treatment of a bleeding disorder. I'll also be talking about the different types of bleeding disorders affecting women, focusing on von Willebrand disease, the most common disorder, and what to do if you suspect you or someone you know may have a bleeding disorder."

5. State the prevalence of von Willebrand disease using the audience as an example.

1 to 2% of the population is believed to be affected by von Willebrand disease.

"If 1 to 2% of the population has this bleeding disorder, _____ women in this group could have a bleeding disorder."

6. Explain to the group why this information/presentation is important to you.

Use the short narrative you created as a guide to





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

explain to the audience how a bleeding disorder has affected your life, prior to and after diagnosis.

Do not overwhelm the women with technical or medical details.

Share this story as a way to make the information real and significant for every woman in the audience.

7. At this point in the presentation, the volunteers should refer to the "Women Can Have Bleeding Disorders" slides in the Project Red Flag Toolkit and their corresponding Speaker's Notes as a guide.

8. Referral Issues

In addition to the information about the National Hemophilia Foundation, provide information about the local chapter and treatment center(s).

Distribute any brochures/information the chapter/treatment center may have available.

9. Ask the audience if they have any questions.

10. Distribute Handouts

11. Closing

Thank everyone for their time and attention.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Restate the prevalence of von Willebrand disease and why it is so important to be well educated about the symptoms of bleeding disorders and many other medical issues facing women today.

Having a bleeding disorder diagnosed better allows women to have control of their lives thereby improving its quality.

Help us educate the community. Please pass this message on to at least two other women that you know.

SPECIAL CONSIDERATIONS

NOTE: ALL GROUPS MUST BE APPROVED THROUGH THE CONTACT PERSON PRIOR TO THE PRESENTATION.

- **Small Group Presentations:**
(5-25 people)

Potential Small Groups

Co-workers	PTA
Sororities	Church
Relatives	Friends
Women's groups	

Others: _____

- Large Group Presentations:





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

(25 or more people)

Current Agreements:

Slides: The slides will primarily be used to the large group presentations

Co-facilitator:

Either a chapter representative or treatment center representative will accompany the volunteer(s) to the large group presentations and assist them during their presentation. Each representative and volunteer pair is free to develop their own plan of action for working together.

Using the Slides:

Slide projector (used with 35mm slides) or laptop (used with PowerPoint presentation):

Volunteers can practice operating the slide projector or laptop at this time.

● **Other ways to convey the message**

GROUP EXERCISE: PERSONAL NARRATIVES

1. Why is being a part of this project important to the volunteers?
2. What would they like to tell the community group about themselves?





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

3. Volunteers should share personal narratives in small groups to get feedback on the narratives' style and content.

PRACTICE PRESENTATION SIGN-UP

Volunteers should:

1. Choose a section of the presentation to conduct
2. Sign up with the trainer before they leave
3. Prepare for the presentation on their own prior to session three

SUMMARY

Main Ideas:

Next Meeting:

Date: _____

Time: _____

Location: _____

III) SESSION THREE

SESSION THREE OBJECTIVES

- Practice presenting in front of a group
- Give and receive constructive feedback





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- Become aware of personal strengths and weaknesses with regard to public speaking
- Understand the Woman-to-Woman timeline
- Prepare for large group presentations

SESSION THREE - PRACTICE AND FEEDBACK

INTRODUCTION

PRESENTATION GROUND RULES

- The presentations should be delivered as if they were being presented to a community group or organization.
- Be aware of the time. Each presenter has between 5 and 10 minutes to complete her section of the presentation. The trainer should let the presenter know when they have 2 minutes remaining. Remember that everyone needs to get a chance to speak.
- Don't interrupt the speakers to comment. Feedback will be provided after the entire presentation has been completed. Volunteers should write down their comments.
- Make sure that everyone knows how to operate the slide projector or laptop before beginning.

PRACTICE PRESENTATION(S)

Presentation Format

- Volunteers 1 through 5 will each do a small portion of the presentation.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- If there are more than 5 volunteers parts of the presentation can be repeated to give everyone a chance to practice.
- Each presentation will take approximately 35 minutes.
- The first 5 volunteers will deliver the presentation followed by guided feedback (guidelines to follow).
- If the presentation or parts of the presentation need to be repeated the volunteers should be allowed to break for about 5 minutes in between each presentation to prepare for the following presentation.

PRESENTATION FEEDBACK

The purpose of the feedback portion of the session is to help the volunteers be the best presenters they can be. It may be difficult not only to receive constructive criticism but also to give it. Remember that if all are positive the speaker will not know what areas need improvement.

Guidelines for Feedback

At the end of the practice session, volunteers should give and receive feedback. This will be done as a group in an informal manner. This feedback will increase the volunteers' awareness of some areas that need improvement. They will become more effective presenters and make a more profound impact on their audiences.

Examples of positive feedback:





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

- "I really liked how you made eye contact with several audience members."
- "Your voice was very clear and easy to hear."
- "The fact that you smiled helped me relate to you."

Examples of constructive criticism:

- "You may not have been aware of this, but you were swaying back and forth and it was a little bit distracting."
- "I had trouble hearing you in the back row. It might help if you didn't look at the slides as much because your head was turned away from the audience."
- "I understood the point of your personal story, but some women who don't know about bleeding disorders may not. I wonder if it would help to clarify the process you went through to get diagnosed."

SMALL GROUP PRESENTATIONS

Community Groups:

1. _____
2. _____
3. _____
4. _____





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

5. _____

6. _____

7. _____

8. _____

WOMAN-TO-WOMAN TIMELINE AND TASK CHECKLIST

1. _____ Volunteer training: Sessions one through Three.
2. _____ The volunteer will create a list of organizations/groups.
3. _____ The volunteer will contact the organization or group to identify the contact person and introduce the project.
4. _____ An introductory letter will be sent to the contact person.
5. _____ The volunteer will follow up with the contact person to schedule a presentation.
6. _____ The volunteer will register the organization/group with the chapter/treatment center representative.
7. _____ Small group presentations will be conducted throughout the two to three months following the training.
8. _____ The volunteer will forward the completed "Community Presentation Forms" to the chapter/treatment center representative.
9. _____ The chapter/treatment center representative will send a thank you letter to the organization or group.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

10._____ The volunteers will participate in training session four.

11._____ Large group presentations will be conducted throughout the two to three months following the training.

12._____ The volunteer will forward the completed "Community Presentation Forms" to the chapter/treatment center representative.

13._____ The chapter/treatment center representative will send a thank you letter to the organization or group.

POST-TRAINING ASSESSMENT

Purpose

The purpose of the pre-training assessment was to measure the volunteers' knowledge of bleeding disorders before the training sessions. The post-training assessment will then measure the volunteers' knowledge of bleeding disorders after the training sessions.

Please note that individual scores will be measured to determine a volunteer's readiness for the community presentations. If a volunteer does not score a 100% on the post-training assessment, she will have a private meeting with the trainer to discuss the questions she missed. The scores will also be used to compare the group's knowledge before and after the training to determine the impact of the training sessions.

Scoring the Pre-Training and Post-Training





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Assessments:

Before the training sessions began the pre-training assessment should have been administered. Scoring can be done following the training session. Each question has a given value of one. To calculate an individual volunteer's score, the trainer should add up all the correct responses then divide that number by the total number of questions in the assessment. Following the training sessions the post-training assessment should be administered and scored. Any questions the volunteers continue to answer incorrectly should be discussed at this time.

To determine the overall impact of the training sessions on volunteers' knowledge, the score on the pre-training assessment and the post-training assessment can be compared. The average number of correct responses for the group of volunteers can be determined by adding the total number of correct responses on all assessments and dividing that number by the total number of volunteers who completed each assessment. Compare these two grand totals to obtain a numerical reading of overall knowledge gains from the training sessions.

SUMMARY

Main Ideas:

Next Meeting:





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

Date: _____

Time: _____

Location: _____

IV) SESSION FOUR

SESSION FOUR OBJECTIVES

The objectives of this session are to:

- Discuss the completed presentations.
- Learn what changes can be made for future presentations.
- Gain support from other presenters.
- Provide new volunteers with an orientation to the Woman-to-Woman project and to medical information about bleeding disorders in women.

SESSION FOUR/ PART ONE - VOLUNTEER NETWORKING

WELCOME AND INTRODUCTIONS

VOLUNTEER NETWORKING

SESSION FOUR/ PART TWO A - NEW VOLUNTEERS (SESSION ONE)

SESSION FOUR/ PART TWO B- RETURNING





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

VOLUNTEERS (DEBRIEFING)

DEBRIEFING THE PRESENTATIONS

Debriefing Guidelines

Ask for a volunteer to begin talking about her experience with the presentations. Ask her to include:

- The nature of the visit (school, friends).
- Positive points about the presentation (people really paid attention, volunteer wasn't nervous).
- Areas to be improved upon (volunteer was nervous, people appeared bored).

Ask for feedback from the other volunteers:

- Did anyone else have these experiences?
- What could have been done differently?

DISCUSSION OF LARGE GROUP PRESENTATIONS

Sign up for large group presentations

Collect materials for presentations

Role of the contact person

Discuss plans for large group presentation with partner.

GROUP LEADERS

One of the goals for the Woman-to-Woman project is for the woman to present and teach the bleeding





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES

disorders information. This project aims to empower both the community and the volunteer presenters.

Group Leader Responsibilities

- Teach sessions one through four.
- Work with the chapter representative to coordinate future:
 - Small group presentations
 - Large group presentations
 - Training sessions

Chapter Responsibilities

- Coordinate the details (i.e. time, location, date, materials, staff) of the training sessions.
- Contact community organizations to organize large group presentations.
- Approve small group presentations.
- Recruit new volunteers.

SUMMARY

Main Ideas:

CLOSING

Please continue spreading the message that "Women Can Have Bleeding Disorders".

Reminder: The contact person must approve all groups before presentations are conducted.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

A volunteer's involvement with this project is vital to its success.

You can make a difference in the lives of women with bleeding disorders.

Thank you.



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders