



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's Project Red Flag Coordinator, Anna DeSimone at (800) 42-HAND1 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 Trainer Manual

The format of the Woman-to-Woman Trainer manual has been designed to encourage consistency in training procedures that will ensure the success of the program. The Woman-to-Woman Trainer 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 Volunteer Manual. It is a point-by-point description of what items will be covered during the training session(s). The left hand column contains Notes to trainer. These are guidelines as to how the information may be presented. The trainer(s) should be sure to read all of the notes as they contain helpful information that is not included in the content column.

Each training session will take approximately one hour and 30 minutes to complete. Sessions One through Four have been designed to be implemented on separate dates. However, if time or distance does not allow for this, Sessions One through Three can be implemented together during an all-day training. Session Four would then follow on a separate date. Another alternative is a weekend, overnight training. The training could begin with a networking brunch/lunch, followed by Sessions One and Two. The volunteers could work on their presentations in the evening. Then Session Three could be implemented the following morning. Again, Session Four would follow on a separate date.

It is essential that the trainer(s) read through the manual in its entirety, with special attention given to the Notes to trainer, in order to plan an agenda and timeline for the training sessions.

Please note that there are various items that are needed for the presentation that are outlined as follows (see Session Two for additional details).

1) 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 group presentations. To order these materials, please contact Anna DeSimone, NHF Project Red Flag Coordinator by phone (800) 42-HANDI ext. 3705 or Adesimone@hemophilia.org. It is essential that the trainer(s) review the Project Red Flag Toolkit especially the "Woman Can Have Bleeding Disorders" slides and speakers notes before beginning the training. Note that the slides are also available in Spanish.

2) Session One contains complex information about the signs and symptoms of bleeding disorders, treatment options, genetics, carrier issues, etc. The purpose is to ensure that participants have a basis from which to deliver consistent messages to the community. You may want to consult with your local hemophilia treatment center for protocols. Additionally, it is also recommended that a nurse coordinator presents this material.



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

3) Please review the additional appendices. These are provided as samples for forms, visual aides and supplemental materials needed to conduct the training. Note that the appendices are located at the end of this binder. You can photocopy the appendices and pass them out to your volunteers during the training sessions.

Also, electronic copies of the appendices are available so you may customize them for your use. The appendices are located on the Project Red Flag Web site at www.projectredflag.org. You may also obtain them by contacting Anna DeSimone, NHF Project Red Flag Coordinator by phone at 800-42-HANDI ext. 3705 or E-mail Adesimone@hemophilia.org.

4) In Session Two, there is a detailed list of materials that the volunteers will need for making small and large group presentations in the community. These include: (note that an asterisk* appears next to the materials that are optional for small group presentations)

- Volunteer manual
- "Women Can Have Bleeding Disorders" Presentation from the NHF Project Red Flag Toolkit (35mm slide or PowerPoint slides may be used). These slides are also available in Spanish
- "Women Can Have Bleeding Disorders" Speakers Notes from the NHF Project Red Flag Toolkit
- Slide projector* or laptop*
- Screen*
- Sign-up sheet (see Appendix A)
- Brochures from the Project Red Flag Toolkit. These brochures are also available in Spanish
- Handouts from Woman-to-Woman appendices
- Project Red Flag Web site
- Coffee, tea, water and a snack*

For additional information or technical assistance, you may contact Anna DeSimone, NHF Project Red Flag Coordinator by phone at 800-42-HANDI ext. 3705 or E-mail Adesimone@hemophilia.org.

Lastly, many of the Woman-to-Woman and Project Red Flag Toolkit components may be downloaded from www.projectredflag.org. There is also a discussion group on the site that has been designed especially for women, girls and parents/guardians of female children affected by bleeding disorders. It is the place for them to ask questions, get appropriate information and responses, and to connect with people who share their interests and concerns. See Appendix S for more information.

We hope that you find these materials useful in conducting outreach activities for women in your local communities



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



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..... 33

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.....40

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

TABLE OF CONTENTS (Cont'd)

- Appendix A: Sample Attendance Form
- Appendix B: Confidentiality Agreement
- Appendix C: Pre-Training Assessment
- Appendix D: Medical Information Worksheet
- Appendix E: Elements of Blood Clotting
- Appendix F: Electrophoretic Analysis of von Willebrand Factor
- Appendix G: Personal Narrative Guidelines
- Appendix H: Conducting the Presentation
- Appendix I: Community Contact Form Letter
- Appendix J: Community Presentation Sign-In Form
- Appendix K: Community Group Registry Form
- Appendix L: Practice Presentation Sign-up Form
- Appendix M: Community Group Thank You Letter
- Appendix N: Post-Training Assessment
- Appendix O: Building Blocks to Identification and Treatment of Bleeding Disorders
- Appendix P: The Process of Blood Clotting
- Appendix Q: Inheritance Pattern in von Willebrand Disease
- Appendix R: References
- Appendix S: NHF Project Red Flag Materials and Order Forms



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

The purpose of the first session is to orient the volunteers to the Woman-to-Woman project and to provide information about bleeding disorders. Although variations in personal presentation style are anticipated, the following objectives are to be used as a guide. The objectives will provide consistency in training procedures that will ensure the success of the program.

Begin by introducing yourself and describing your role in the project. Have any co-trainers do the same. Introduce the contact person-chapter/association representative. Ask them to describe his/her role in the project.

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

The volunteers should write the name and phone





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Please make the women aware that there will be time for questions at the end of the training, but that they are also free to ask questions throughout.

Hand out the Volunteer Manual. The manual is theirs to keep. They should bring it to all sessions.

Please refer to Appendix A: Attendance Form for a sample.

Explain to the volunteers that these goals will be accomplished by training them and others to go out into their communities and deliver presentations about bleeding disorders that affect women. Through this training, they will have the tools necessary to do an effective presentation.

number of the contact person in their manual.

Contact Person: _____

Phone Number: _____

Other important information:

- **Restrooms:** Please indicate where they are located.
- **Breaks:** Please inform the volunteers when breaks (if any) will be taken. If there are no planned breaks, inform the volunteers that they may feel free to get up and use the restrooms as needed.
- **Promptness:** Alert the volunteers to the importance of being prompt for future sessions. Explain the importance of all that is planned for each session and that timeliness will be 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,



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

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 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,





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

The small group presentations will be done following session three. Each volunteer will be asked to complete 2 to 3 small group presentations.

The large group presentations will ideally be done after session four. Each participating chapter will conduct two large-scale presentations that may be carried out by volunteers and chapter/association or treatment center staff.

Staff should plan for one make-up session after the first three, but before session four. The volunteers should be strongly encouraged to use the make-up session for emergency situations only. (The subject matter in the make-up session may vary according to the information missed.)

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.

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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Elicit other ground rules to follow during the sessions from the volunteers. Examples are listed.

Other ground rules:

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

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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Have the volunteers sign the confidentiality form. They must return the signed copy to you to keep on file before continuing with the training. An additional copy is provided in their manual for their reference.

Please refer to Appendix B: Confidentiality Agreement for the handout.

Trainers should have a list of all volunteers participating in the Woman-to-Woman project. When confidentiality agreements are received, a check box should be available on the list to indicate its receipt. Again, please refer to Appendix A for an example.

At this time administer the pre-training assessment and describe the purpose of this test to the volunteers. Please refer to Appendix C for the Pre-Training Assessment.

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

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.

Answers to the Pre-Training Assessment:

1. T
2. E





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Correct the assessments with the volunteers, explaining that these questions will be answered in detail during the following sessions. Collect the assessments and file for use later.

Ask the participants to introduce themselves. Let them know that they will have the opportunity to talk more with each other at the end of the session.

The idea behind these introductions is to allow the women time to get to know each other but still be focused on the purpose of the training. In asking the women to give more information at the outset, you risk altering the training atmosphere to that of a support group.

To highlight this point, it will be useful to calculate how many women in your state potentially have von Willebrand disease. Compare this to how many women are currently being seen in the HTC's in your state. Your CDC/MCHB regional coordinator should have this information.

3.D
4.F
5.C
6.T
7.C
8.D
9.T
10.F
11.F

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
- 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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Ask the volunteers to give examples of physical and psychological consequences of an untreated bleeding disorder. Supplement their ideas with the list provided.

- 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

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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

The intention of part two is to educate the volunteers on the signs and symptoms of bleeding disorders and the medical management of bleeding disorders. This instruction will ensure that all participants have a basis from which to deliver a similar message to the community. It is recommended that a nurse coordinator present the following material. Please refer to both the "Women Can Have Bleeding Disorders" slides in the NHF Project Red Flag Toolkit and the volunteer manual to guide the volunteers through this part of session one. Allow time for questions. Personal questions specific to a volunteer's bleeding disorder should be answered after the session.

Please refer to Appendix D: Medical Information Worksheet. This appendix may be a helpful tool in creating a master sheet of medical information for the volunteers. Volunteers can use this sheet to take diagnosis-specific notes during the presentation. Designing a flip chart that resembles the worksheet may be an effective visual aid during the lecture.

be addressed.

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.
- 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



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Please refer to Appendix E: The Elements of Blood Clotting and Appendix P: The Process of Blood Clotting to aid in the description of the blood clotting process.

Use the "Woman Can Have Bleeding Disorders" slides 3,6,7 in the Project Red Flag Toolkit as visual guides.

Point out to volunteers that the acronym H.E.L.P.U. is an easy way to remember the symptoms experienced by women with bleeding disorders.

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, moderate 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:





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Use the "Woman Can Have Bleeding Disorders" slides 4,5 in the Project Red Flag Toolkit as visual guides. As an introduction to von Willebrand disease review with the volunteers the role of von Willebrand factor in the blood clotting process.

- 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.

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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Appendix F: Electrophoretic Analysis of von Willebrand Factor can also be used to further explain von Willebrand Disease.

As an introduction to carriers of hemophilia, review with the volunteers the role of clotting factors in the blood clotting process. It may also be important to discuss how a woman is determined to be a carrier. Genetics will be discussed later so an introduction is sufficient at this time.

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.

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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

As an introduction to platelet function defects, review with the volunteers the role of platelets in the blood clotting process.

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

- 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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Use the "Women Can Have Bleeding Disorders" slides 8,10 in the Project Red Flag Toolkit as visual guides.

Use this time to preface the genetic information that will be discussed later. Discuss with the group how people present and reinforce the information on the signs and symptoms of bleeding disorders. Please consult with your local treatment center for testing protocols. Also, use this time to explain the effects of birth control pills, stress and other factors that can have on the results of these tests. Many times a laboratory test may have to be repeated before a diagnosis can be confirmed.

Use the "Woman Can Have Bleeding Disorders" slides 9,10 in the Project Red Flag Toolkit as visual guides.

- 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
- 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 indi-





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

cates 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 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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

At this time you may also choose to discuss the treatment for factor IX carriers.

Ask the volunteers if they have any further questions about treatment options.

At this time, there is no cure for a bleeding disorder. Gene therapy is on the horizon. Briefly discuss with the group the basis of gene therapy. The symptoms of a bleeding disorder can be adequately managed today with safe, modern therapies. With these therapies, people with bleeding disorders can lead active, normal and productive lives.

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 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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Using the illustration in Appendix Q: Inheritance Pattern in von Willebrand Disease, discuss how von Willebrand disease can be passed from one generation to next. It will also be important to note that platelet function defects also run in families.

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 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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Identify the local and national resources available to the bleeding disorders community.

Highlight the main ideas of this session as an overview. Ask the volunteers if they have any questions. Distribute any handouts that would enhance the presentation. Review the instructions for the homework assignment.

- 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.
- 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:





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Local Treatment Center Network:

National Organization:

NHF has many resources available as part of its 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: _____





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Using the Personal Narrative Guidelines provided in Appendix G ask the volunteers to 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. Have them describe in general their experiences living with a bleeding disorder. Please note that graphic details are not necessary and might frighten a group of women who know little about bleeding disorders.

Allow the women some time at the end of session one to talk with one another over beverages and snacks. The time frame is to be determined by the trainer.

Have the volunteers sign in. If any new volunteers are present for this session please have them sign the confidentiality statement before beginning the session. The purpose of part one of the second session is to teach the volunteers effective techniques for the presentation.

Introduce yourself to the group, and have them introduce themselves briefly. Using Appendix O, the building blocks graphic in session one briefly review highlights from the medical information presented in that session. Ask the group if there are any questions from the last session.

"Conducting the Presentation" handouts, Appendix H may be a helpful visual aid during the discussion.

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.

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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

To open the discussion, ask the volunteers about their experiences with public speaking. The trainer should also share his/her stories with the group. Relate these previous speaking experiences to the information presented throughout the remainder of Session two/part one.

Drawing from the volunteers' experiences as audience members, identify things speakers have done that have made presentations clear and interesting. Add the skills provided to the list that the volunteers create or use to begin the discussion.

- 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

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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Drawing from the volunteers' experiences as audience members, identify things speakers have not done that have resulted in an uninteresting or distracting presentation. Add the points provided to the list that the volunteers create or use to begin the discussion.

- 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 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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

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 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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

The following information will guide the volunteer through the community presentations. This part of session two will describe in detail how the volunteer should conduct the presentation using the Project Red Flag slides developed by the National Hemophilia Foundation and supplemental materials.

A group or individual exercise can be done at this time to help the volunteers brainstorm about contacts. Ask the group of volunteers to list contacts in their community. Volunteers can help one another create a list of organizations and businesses in their communities that would fit into each of the categories.

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 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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

An example of an introductory letter is in Appendix I for reference.

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.

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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

For a successful presentation, the volunteers will need the following materials. The volunteer will bring some of these materials to the presentation, others will need to be coordinated with the community organization. For small group presentations these materials are optional. ()*

Please review with the volunteers the recommended order of the presentation. Allow for time throughout for questions. Let the discussion be directed by the step-by-step outline that follows.

Please refer to Appendix J: Community Presentation Sign-Up Form when describing step one.

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. 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)





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

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*

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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

For step #7, the trainer should present the slides "Women Can Have Bleeding Disorders" slides in the NHF Project Red Flag Toolkit in their entirety.

Speaker's Notes: contains a step-by-step script for the presentation. Although it is not intended to be read word-for-word, the outline guides the process of the presentation. As the volunteers become more familiar and comfortable with the slides and the presentation as a whole, she will find that she relies less and less on the Speaker's Notes. At no time is the volunteer expected to have memorized all the information and conduct a presentation without the Speaker's Notes or supplemental materials.

Slides: Use this time to explain that the slides prepared by the National Hemophilia Foundation focus on the most common bleeding disorder, von Willebrand disease. The other bleeding disorders material presented in session one will be useful in fielding questions the audiences may have. This information should also increase the volunteer's level of comfort with sharing her story should her bleeding disorder be one other than von Willebrand disease. After showing the slides ask the volunteers if they have any questions.

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.

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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Ask volunteers for ideas about small groups in their communities that may be interested in hearing the information. The goal is to have between 5 and 10 women in the audience.

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 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).





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Explain to the volunteers that they should register and get approval for their proposed small group presentation. You can collect this information using Appendix K: Community Group Registry Form.

Ask the contact person to discuss with the volunteers the arrangements that have been made with the large community organizations/businesses. The contact person will primarily be responsible for coordinating the large group presentations.

Use this time to demonstrate to the volunteers how to use a slide projector or laptop. Allow time for the volunteers to personally try operating the equipment.

Due to the fact that using the slides are optional for small group presentations, brainstorm with the volunteers about different ways to convey the message. Have the volunteers think of things they'd like to do to enhance the presentation. Have them write these ideas down for future reference. Examples follow.

*Flip charts
Music*

*Poster board
Pictures*

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.

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)





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Ask the volunteers to split up into small groups where they can share their personal narratives to get feedback on the style and content. Give the groups approximately 15 minutes to complete their discussion and then ask the women to share an edited narrative with the larger group.

The volunteers will conduct a presentation during session three. Please refer back to pages in this section for a specific description of each step. The sequence of the presentations is as follows:

1. Volunteer 1 will present Steps 1 to 5,
2. Volunteer 2 will share her personal story (Step 6),
3. Volunteer 3 will present Slides 1 to 6, (first half of Step 7)
4. Volunteer 4 will present Slides 7 to 12, (second half of Step 7)
5. Volunteer 5 will present Steps 8 to 11.

Please refer to Appendix L, Practice Presentation Sign-Up Form. Note that the presentation or parts of it may have to be conducted more than once. It is recommended that each volunteer be given a chance to present in front of the entire group and receive feedback. If necessary, split the volunteer group into two sections and them run simultaneously (two rooms needed). Remind the volunteers of other ways to convey the message. They may use the ideas to enhance their presentations during session three. Ask the volunteers to review their manuals and Speaker's Notes, to practice their presentations at home and begin organizing opportunities to deliver the Woman-to-Woman project in their communities.

Potential Small Groups

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

Others: _____

- Large Group Presentations:
(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):





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Review the main ideas covered in the session. Ask for feedback on the slides. Distribute a copy of the "Women Can Have Bleeding Disorders" Slides and Speaker's Notes to each of the volunteers.

Describe the focus of session three. Refer back to the Presentation Steps in the manual.

Have volunteers sign in. The purpose of this session is to give the volunteers a chance to practice part of the presentation and to see the presentation in its entirety. This is also an opportunity for them to give and receive feedback.

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?
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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Introduce yourself and review the objectives for this session. Review the order in which the women will present based on the schedule created during session two.

Before the presentations begin, review the ground rules for presenting the information and providing feedback.

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
- 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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

The purpose of the feedback portion of the session is to help the volunteers to be the best presenters that they can be. Volunteers may find it difficult not only to receive constructive criticism but also to give it. Remember that if all of the comments are positive, the speaker will not know what to work on.

Have the volunteers offer and ask for positive feedback statements and statements about needed improvement. Receiving suggestions for improvement does not mean that a volunteer did a poor job, rather it will increase their awareness that some changes could improve their ability to get the point across. The goal, after all, is to have the groups really listen to what they say and take it to heart.

Ask the presenters if they have other specific items that they would like feedback on. Ask the volunteers if they have any questions about how the presentations should look when they do them alone.

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.
- 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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Ask the volunteers to identify the community groups to which they will be presenting in the next couple of months. Have the volunteers complete a form registering their presentations with the trainer. This form will be helpful in tracking the number of presentations that have been delivered. This information can then be forwarded to the contact person. A sample is provided in Appendix K. At this time, it will also be important to answer any questions the volunteers may have about the small group presentations. Remind the volunteers that the contact person must approve each presentation, and that person will contact the volunteer to discuss the presentations listed on the registry form.

Distribute the materials (listed in session two/ part 2) that the volunteers will need for their presentations.

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:

- "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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

At this time, review the timeline with the volunteers so that they have a clear understanding of what is expected of them. You may adjust the timeline to meet your programming needs. This timeline can also be used as a task checklist for both the contact person and volunteers.

This list of tasks may appear overwhelming at first. Trainers should emphasize that these steps are taken over a few months time and discuss the specific timeline created by the contact person. At this time, trainers may also want to highlight the individual responsibilities of the people involved (contact person, volunteer, etc.)

Please refer to Appendix I again to describe the introductory letter.

Please refer to Appendix M: Community Contact Thank You Form Letter when describing the thank you letter.

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. _____
5. _____
6. _____
7. _____
8. _____

WOMAN-TO-WOMAN TIMELINE AND TASK





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

At this time, administer the post-training assessment and describe the purpose of this test to the volunteers.

Please refer to Appendix N for the Post-Training Assessment.

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.
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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

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.

Answers to the Post-Training Assessment:

1. F
2. T
3. E
4. D
5. T
6. C
7. T
8. T
9. T





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Inform the volunteers that the group will not meet again until after they have done the small group presentations. If the volunteers have any questions they should call their contact person. During session four the group will discuss how the presentations went and prepare for the large group presentations. New volunteers will also be at session four. They will start their training at that meeting and continue with the sessions as this group has done. If the volunteers know of other women with bleeding disorders who may want to participate in this project please let the trainer know so that they can be invited to participate. The trainer should have a sign up sheet available for the volunteers to provide the names and phone numbers of women they feel would be. Introduce yourself, the contact person and any co-trainers and explain your role(s). Have the participants briefly introduce themselves and tell the group if they are a new or returning volunteer.

Provide snacks and beverages for volunteers and allow them approximately 15-20 minutes to socialize. After 20 minutes, separate the group into new and returning volunteers and begin part two.

10.T
11.T

Scoring the Pre-Training and Post-Training 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:





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

This portion of the session should be relatively informal with the trainer asking questions and directing the debriefing as necessary. Keep in mind that each volunteer should only have approximately 5 minutes to discuss their presentations in order to address all volunteers. It should not, however, be mandatory that each volunteer share. Many people learn by listening and will use the information shared for their own future presentations.

At this time the volunteers should sign up for the large group presentations coordinated by the chapter. A chapter representative should be available to discuss with the group the arrangements that have been made. Every large group presentation will have two volunteer presenters. If necessary, the volunteers should pair up with a treatment center or chapter representative for support. Time should be set aside during this session to allow these pairs to discuss how they plan to deliver the Woman-to-Woman project.

Next Meeting:

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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

Please distribute the materials (as listed in session two/part 2) that the presenters will need.

One of the goals for the Woman-to-Woman project is for the woman to present and teach the bleeding disorders information. This project aims to empower both the community and the volunteer presenters. At this time ask the group of volunteers if anyone would be interested in leading the next group of volunteers through the Woman-to-Woman project.

Review with the volunteers the points highlighted during the debriefing. These are important to remember when presenting in the future whether it be for the Woman-to-Woman project or another project. Speak with any volunteers interested in becoming a group leader separately after the closing of the session.

Thank the volunteers for their help. Wish them luck on their large group presentations and tell them the contact person will be contacting them following their presentations. Encourage them to continue to pursue other avenues for presenting the Woman-to-Woman in their communities. Reminder: all presentations must be approved through the contact person.

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

SESSION FOUR/ PART TWO B- RETURNING 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.





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

GROUP LEADERS

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





Project Red Flag
Real talk about women's bleeding disorders

WOMAN-TO-WOMAN

NOTES TO TRAINER

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

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



WOMAN-TO-WOMAN CURRICULUM

Appendix A

Attendance List:

Volunteer Name:

Confidentiality Agreement Received:

- | | |
|-----|--------------------------|
| 1. | <input type="checkbox"/> |
| 2. | <input type="checkbox"/> |
| 3. | <input type="checkbox"/> |
| 4. | <input type="checkbox"/> |
| 5. | <input type="checkbox"/> |
| 6. | <input type="checkbox"/> |
| 7. | <input type="checkbox"/> |
| 8. | <input type="checkbox"/> |
| 9. | <input type="checkbox"/> |
| 10. | <input type="checkbox"/> |



WOMAN-TO-WOMAN CURRICULUM

Appendix B

To participate in the Woman-to-Woman project this agreement must be signed.

CONFIDENTIALITY AGREEMENT

I have been informed of the need to protect the confidentiality of all personal information shared during the training sessions and the presentations in which I am involved.

I understand that not only is this right of confidentiality granted to individuals under state and federal confidentiality laws, but that it is important for all Woman-to-Woman participants to feel comfortable sharing information in order for the goals of the Woman-to-Woman project to be achieved.

I agree to maintain the confidentiality of personal information shared by participants in all phases of the Woman-to-Woman project as discussed during my training and in the Woman-to-Woman Volunteer Manual.

Name

Date



Project Red Flag
Real talk about women's bleeding disorders
NATIONAL HEMOPHILIA FOUNDATION

WOMAN-TO-WOMAN CURRICULUM

Appendix C

Pre-training Assessment:

1. A bleeding disorder is a flaw in the body's blood clotting system. T F
2. Bleeding disorders are caused by a _____.
 - a. low level of clotting factors in the bloodstream
 - b. defect in the clotting factor in the bloodstream
 - c. defect in the platelets in the bloodstream
 - d. a and c
 - e. all of the above
3. Of the several types of bleeding disorders which affect both men and women equally?
 - a. Hemophilia A
 - b. Christmas Disease
 - c. Factor IX deficiency
 - d. von Willebrand disease
4. Hemophilia is the most common inherited bleeding disorder. T F
5. von Willebrand disease is thought to affect as many as _____ of the population.
 - a. .5%
 - b. 7-10%
 - c. 1-2%
 - d. 6%
6. von Willebrand disease is a genetic disorder. T F
7. A carrier is someone who _____.
 - a. carries the bleeding disorder gene.
 - b. can have similar symptoms as someone with a bleeding disorder
 - c. a and b
 - d. none of the above
8. Symptoms of von Willebrand disease include: _____.
 - a. easy bruising
 - b. nose bleeds
 - c. gum bleeding
 - d. all of the above
9. Diagnosing an individual with a bleeding disorder involves taking the individual's medical history, and performing a physical examination and specialized laboratory tests. T F

10. Only one treatment is available for individuals with bleeding disorders.

T F

11. If an individual suspects they may have a bleeding disorder they should contact_____.

- a. the local chapter
- b. their primary physician
- c. a local hematologist
- d. the local hemophilia treatment center
- e. the National Hemophilia Foundation
- f. all of the above



WOMAN-TO-WOMAN CURRICULUM

Appendix D

Medical Information Worksheet:

	Hemophilia	Hemophilia Carrier	von Willebrand Disease	Platelet Function Defect
Signs and Symptoms				
Diagnosis				
Treatment				
Genetics				



WOMAN-TO-WOMAN CURRICULUM

Appendix E

The Elements of Blood Clotting:

Handout #1:

The circulatory system is made up of blood vessels like arteries, veins and capillaries.

Handout #2

von Willebrand protein, platelets and clotting factors are circulating in the blood stream in an inactive state, basically waiting to do their job in case there is injury to the blood vessel wall.

When blood clots it is like a drama, in particular, like a three part play. In the introduction of the drama, an injury to the blood vessel occurs.

Handout #3:

During Act I of the play, von Willebrand protein, along with platelets, come to the site of bleeding and start the blood clotting process.

The von Willebrand protein is activated and binds to the exposed blood vessel wall (much like cement holding bricks together).

In turn, von Willebrand protein binds to the platelets localizing them to the injured site.

As the von Willebrand protein and platelets bind together, a platelet plug is formed. This plug slows the flow of bleeding.

If there is a problem with either the ability of the platelets to clump together or with the von Willebrand protein's ability to bind the platelets to the site of injury, bleeding may continue. This person would have a bleeding disorder, either von Willebrand disease or a platelet function defect.

Handout #4:

In Act II of the play, fibrin takes center stage. The clotting factors become activated, interacting with each other in a domino fashion, triggering the formation of fibrin. Fibrin is a jelly-like substance that stabilizes the platelet plug and makes it stronger. The fibrin can also be thought of as the thread that knits the platelet plug together forming a clot.

If a person is missing one of the clotting factors (domino) or if one of the clotting factors doesn't work properly, bleeding may continue. This person would have hemophilia or another rare bleeding disorder.

Handout #5:

Act III brings a happy conclusion to the bleeding episode. The stable clot stops the bleeding and the blood vessel begins to heal.

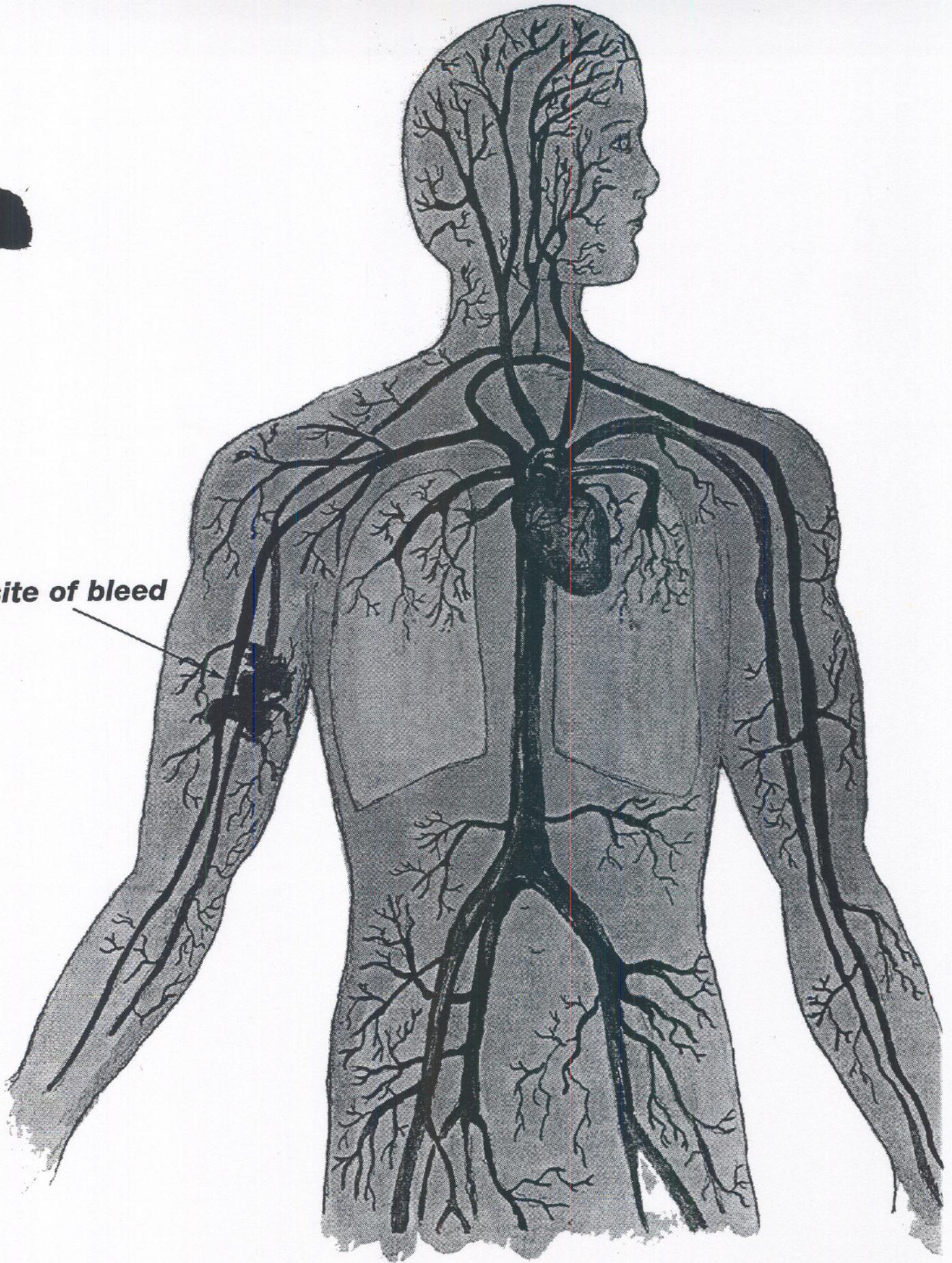
As the blood vessel begins to heal the clot shrinks in size.

Handout #6

The clot continues to decrease in size until the blood vessel is completely healed and no longer requires a clot to protect the once exposed wall. The End.

Without the proper function of the platelets or the von Willebrand protein bleeding would continue. Without the proper function of the fibrin the platelet plug would not be stabilized and an incomplete clot would be formed. Thus bleeding symptoms would be prolonged.

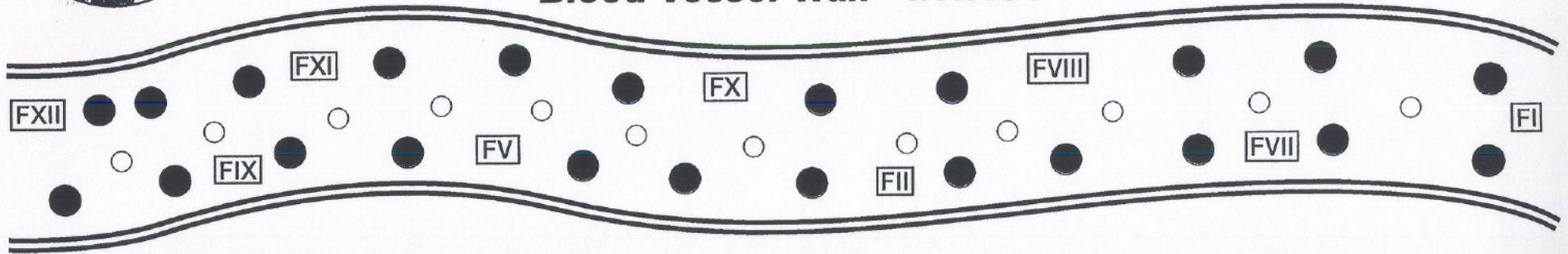
site of bleed



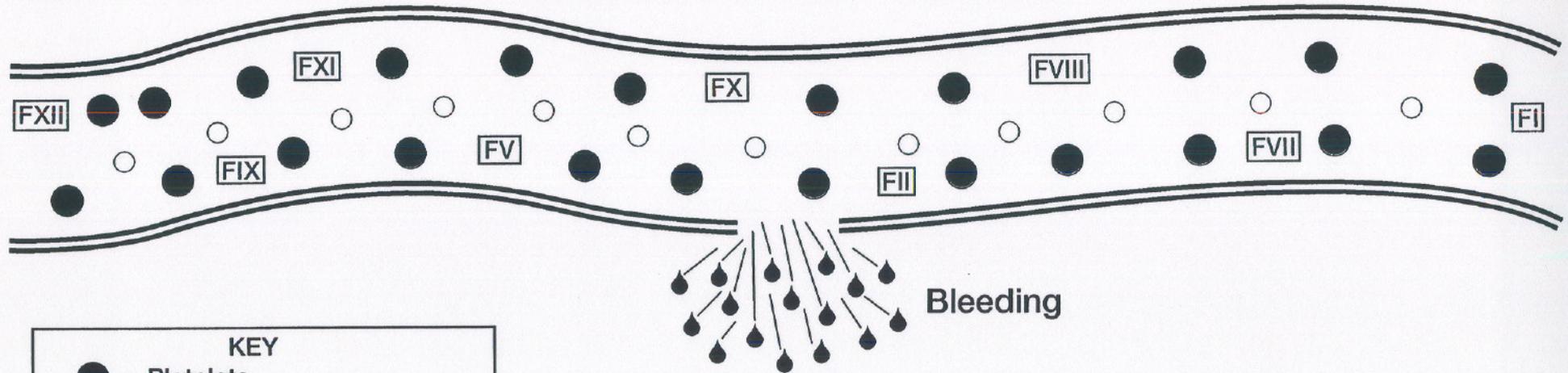
INTRODUCTION



Blood Vessel Wall—INTACT



Blood Vessel Wall—INJURED

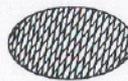


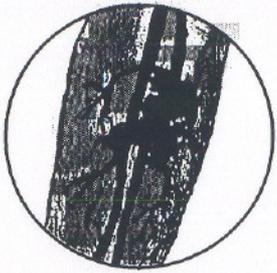
KEY

- = Platelets
- = von Willebrand Protein

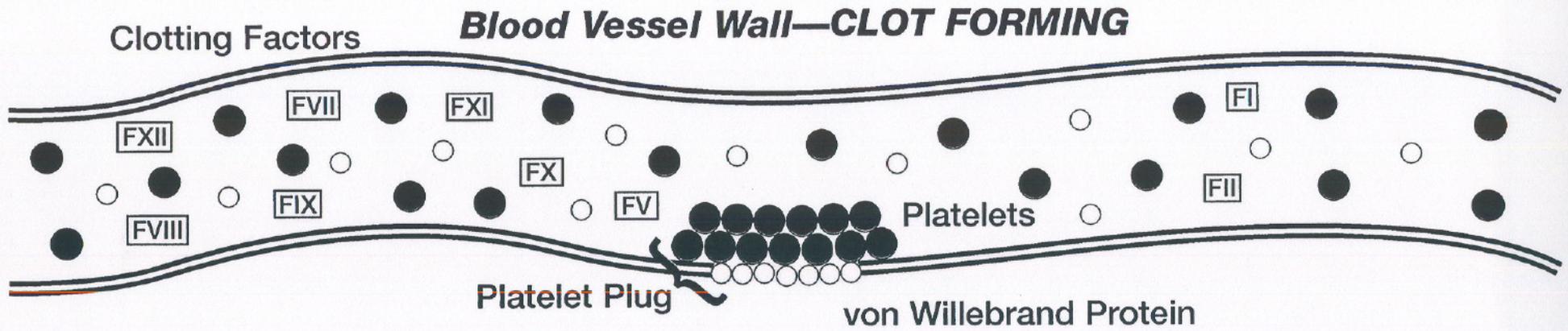
FX	FIX
FXI	FV
FVIII	
FXII	FVII
FII	FI

☞ = Clotting Factors

 = Fibrin



ACT I



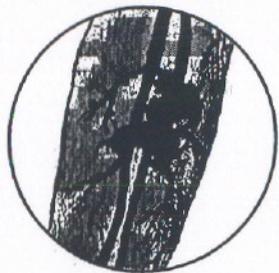
KEY

- = Platelets
- = von Willebrand Protein

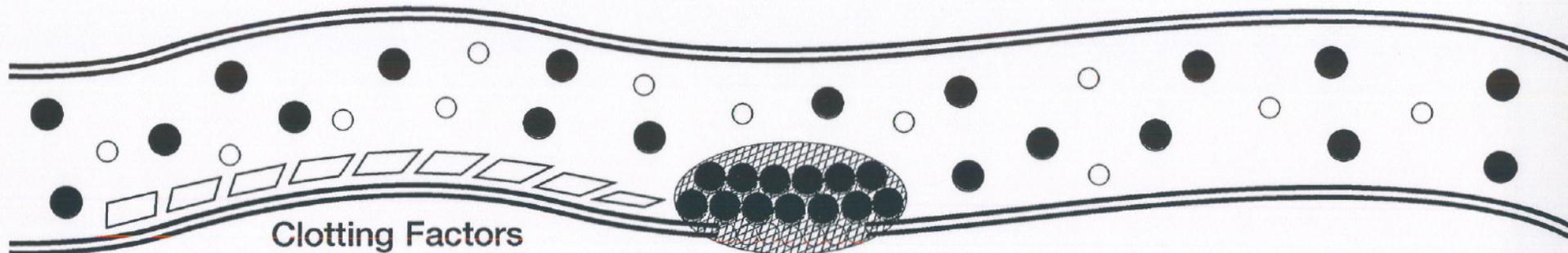
FX	FIX	= Clotting Factors
FXI	FV	
FVIII		
FXII	FVII	
FII	FI	

= Fibrin

ACT II



Blood Vessel Wall—CLOT FORMED



Clotting Factors

Fibrin

Platelet Plug

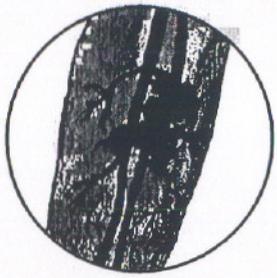
+
Fibrin
=
Clot

KEY

- = Platelets
- = von Willebrand Protein

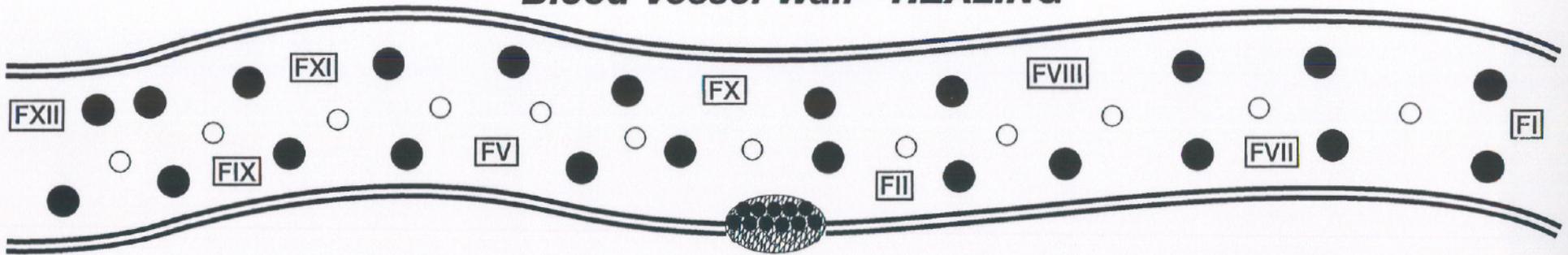
FX	FIX	= Clotting Factors
FXI	FV	
	FVIII	
FXII	FVII	
FII	FI	

● = Fibrin



ACT III

Blood Vessel Wall—HEALING

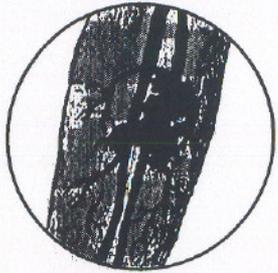


KEY

- = Platelets
- = von Willebrand Protein

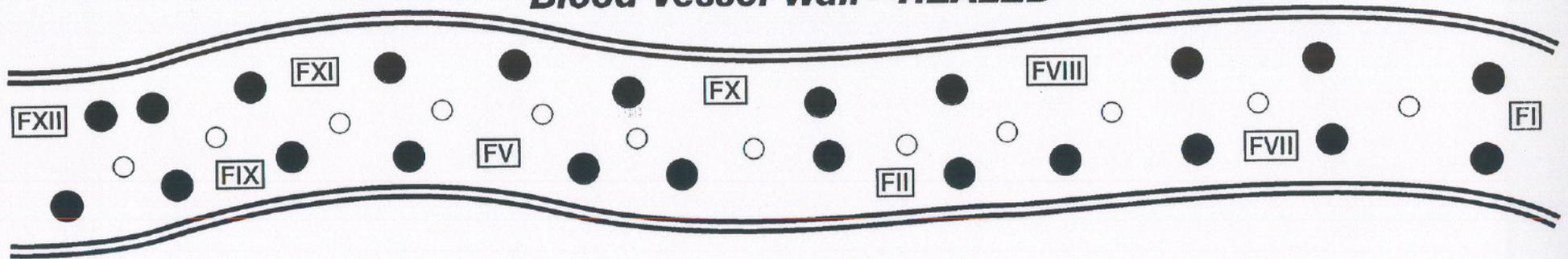
FX	FIX	= Clotting Factors
FXI	FV	
	FVIII	
FXII	FVII	
FII	FI	

= Fibrin



ACT III

Blood Vessel Wall—HEALED



KEY

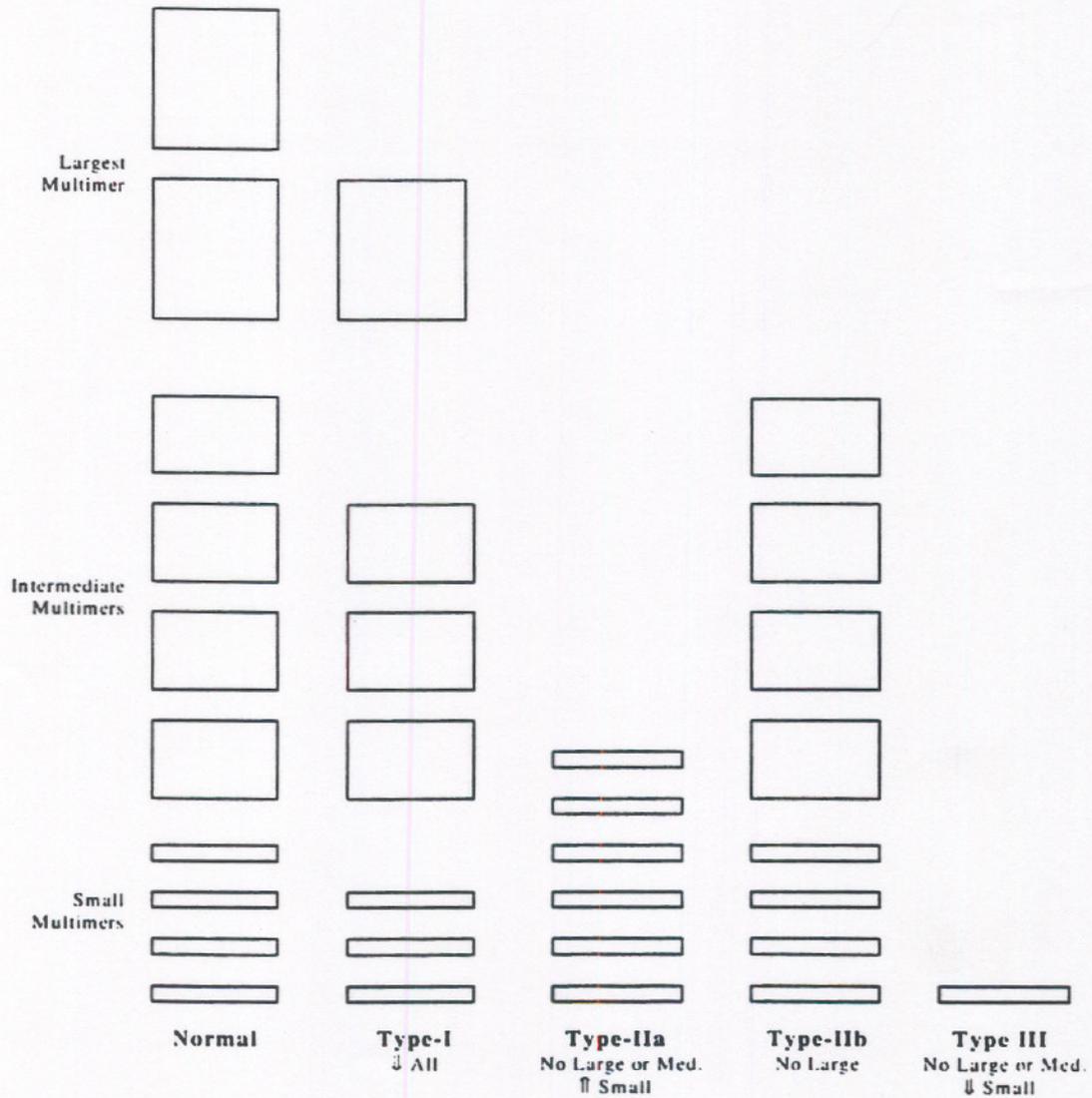
- = Platelets
- = von Willebrand Protein
- | | |
|-------|------|
| FX | FIX |
| FXI | FV |
| FVIII | |
| FXII | FVII |
| FII | FI |

 = Clotting Factors
-  = Fibrin

APPENDIX F

von Willebrand Disease

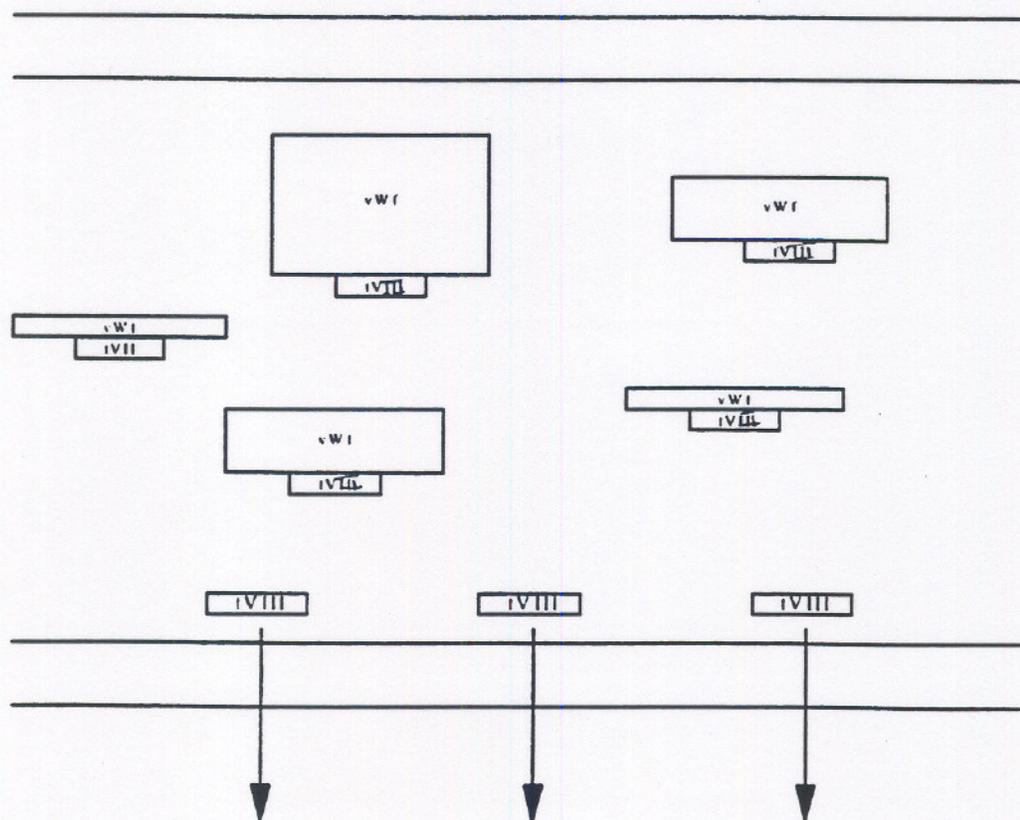
Electrophoretic Analysis of von Willebrand Factor



von Willebrand Disease

- TYPE I

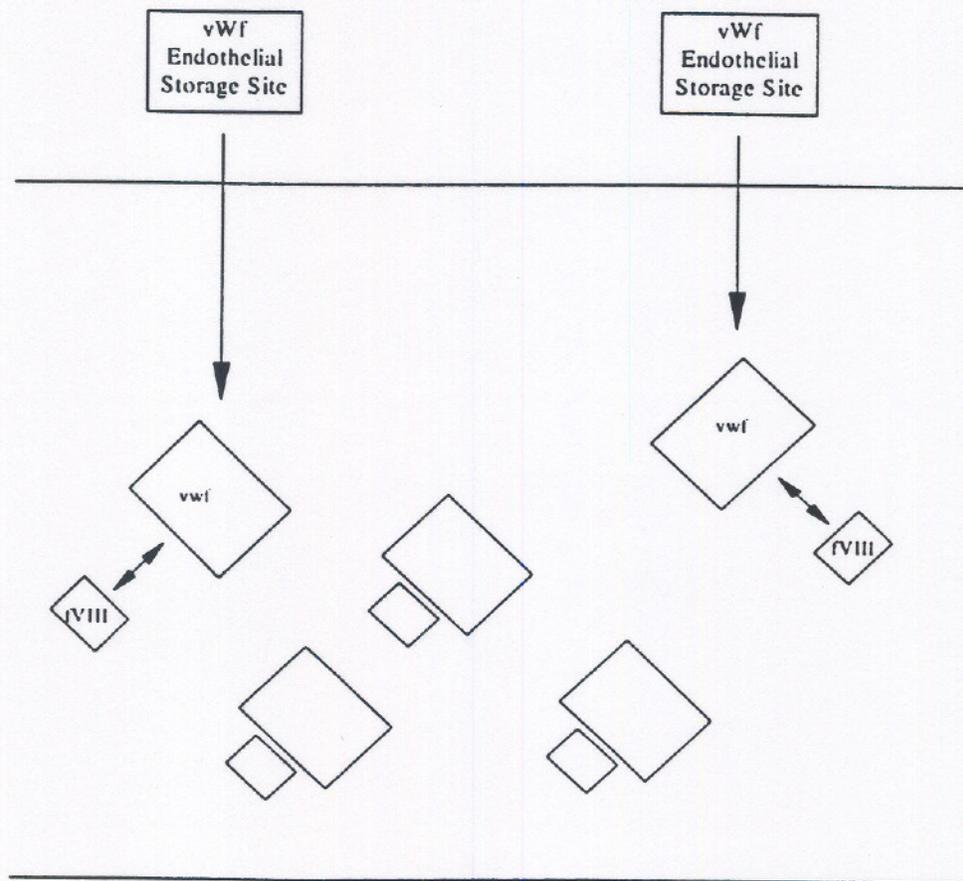
- A decrease in the circulating level of all sizes of the von Willebrand protein.
- can lead to a decreased factor VIII level.



von Willebrand Disease

- TYPE I- TREATMENT

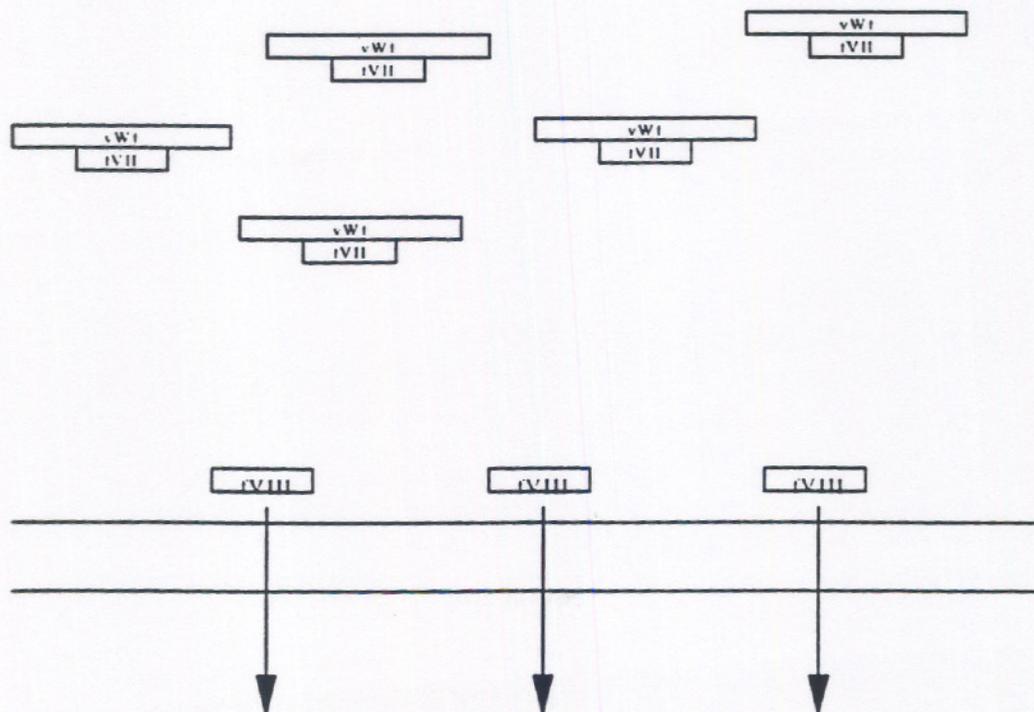
- DDAVP can be given IV, SQ or intranasally.
- Stiminate nasal spray (1.5mcg/ml) is the optimal treatment.



von Willebrand Disease

- TYPE II-A

- lacks both medium and large multimers
- has increased levels of the small multimers



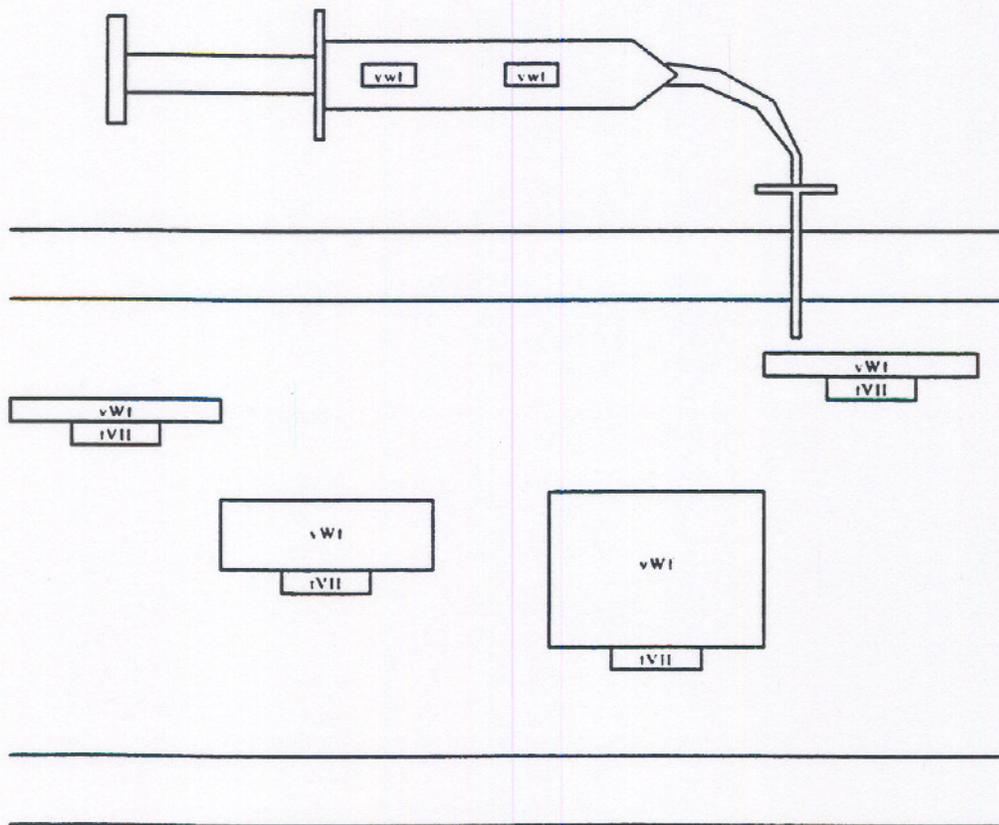
von Willebrand Disease

- Type II-B
 - gain function abnormality causes an increase in the affinity to platelets
 - this affinity can cause varying degrees of thrombocytopenia*
 - gain of function causes the destruction of the large multimers

** Thrombocytopenia - Thrombocytopenia is a disorder in which the number of platelets (a type of blood cell) is abnormally low, sometimes associated with abnormal bleeding.*

von Willebrand Disease

- TREATMENT- TYPE II AND TYPE III
 - Humate-P is a factor VIII concentrate with intact von Willebrand protein



von Willebrand Disease

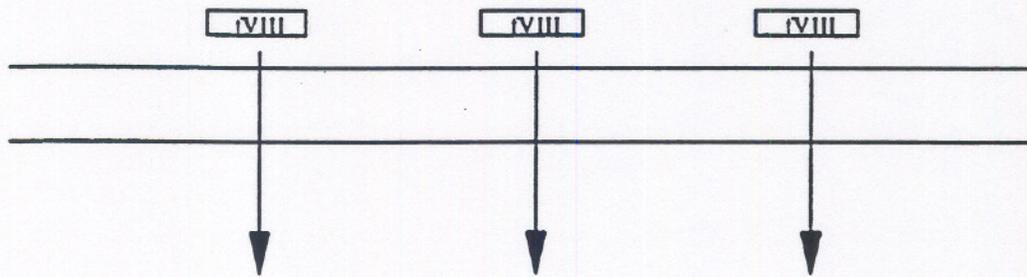
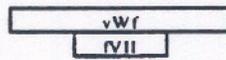
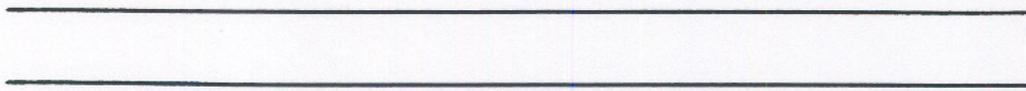
- GENETICS- TYPE I AND II
 - Autosomal Dominant
 - Variable Penetrance and Expression
 - 50% Chance of Transmission With Each Birth

	a^{vwd}	a
a	aa^{vwd}	aa
a	aa^{vwd}	aa

von Willebrand Disease

- TYPE III

- A low level or absence of vWf
- a low level of factor VIII due to instability



von Willebrand Disease

- GENETICS- TYPE III
– autosomal recessive

	a^{vwd}	a
a^{vwd}	$a^{vwd} a^{vwd}$	$a^{vwd} a$
a	$a^{vwd} a$	aa
	a^{vwd}	a^{vwd}
a	$a^{vwd} a$	$a^{vwd} a$
a	$a^{vwd} a$	$a^{vwd} a$



WOMAN-TO-WOMAN CURRICULUM

Appendix G

Personal Narrative Guidelines:

1. Name:
2. Type of Bleeding Disorder:
3. Are other family members affected by this bleeding disorder? If so, who and how are they affected?
4. What are the three most important reasons you decided to participate in this project?
 - A.
 - B.
 - C.
5. What has been your experience getting a diagnosis for your bleeding disorder (include the age at which you were diagnosed)?
6. What has been your experience obtaining treatment for your bleeding disorder?
7. How has having a bleeding disorder affected your life? Your day-to-day activities?
 - A.
 - B.
 - C.
8. What are the three most significant aspects of your bleeding disorder that you would like to change and why?
 - A.
 - B.
 - C.
9. If you could only communicate **one** aspect of living with a bleeding disorder, what would you choose to say?



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

WOMAN -TO- WOMAN

Conducting the Presentation



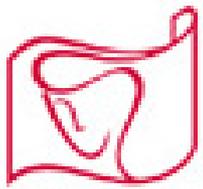
Project Red Flag
Real talk about women's bleeding disorders

In partnership with



ZLB Behring

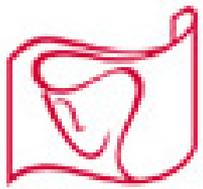




Session Two Objectives

- 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

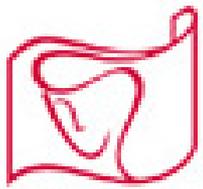




Session Two Objectives

- Learn the skill of networking
- Identify possible groups for future presentations
- Become comfortable with sharing personal stories
- Begin to develop a comfort level with presenting in front of a group

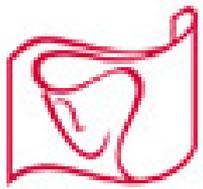




Reducing Anxiety

- Organize
- Visualize
- Breathe
- Relax

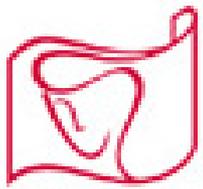




Reducing Anxiety

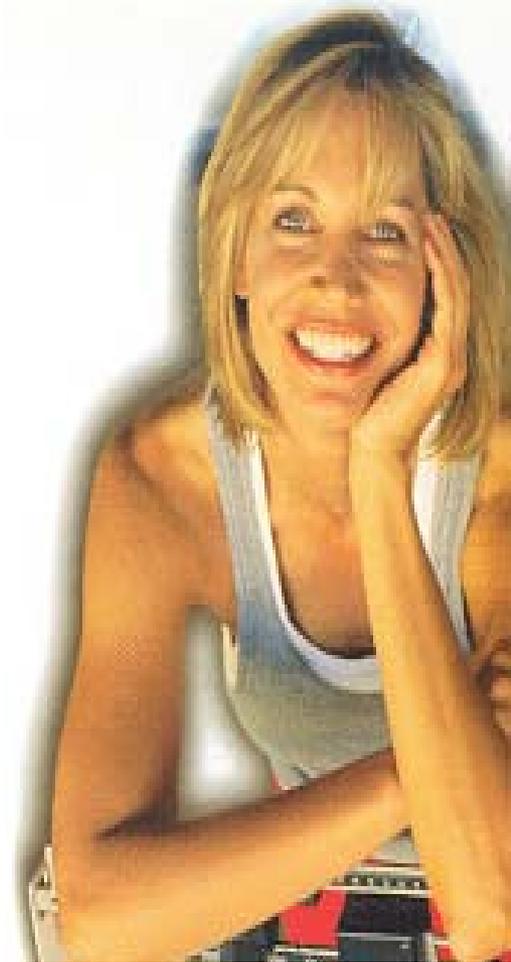
- Release tension
- Move
- Eye contact
- Practice...Practice...Practice

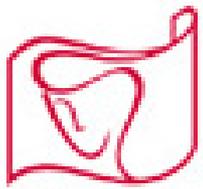




Presentation Do's

- Focus
- Speak slowly
- Use visual aids

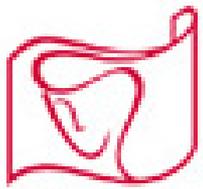




Presentation Do's

- Posture
- Movement
- Shoulder orientation
- Gestures
- Eye contact

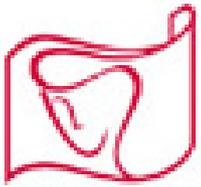




Presentation Don'ts

- Feel like you have all the answers
- Fidget
- Look down
- “Um”
- Go off on a tangent

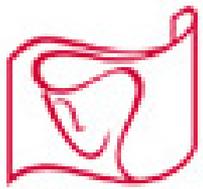




How to Practice

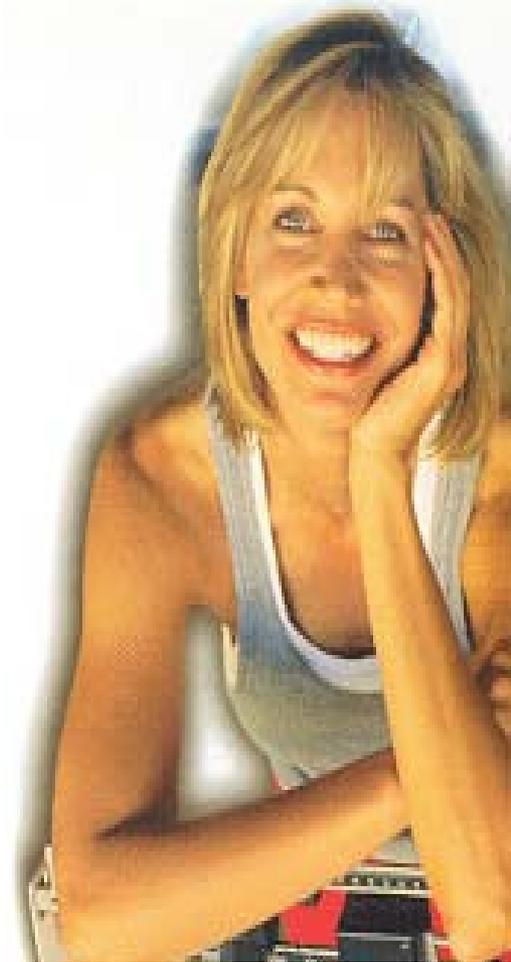
- Notes
- Run through the presentation
- Stand-up practice
- Give practice dress rehearsal
- Practice answers to questions

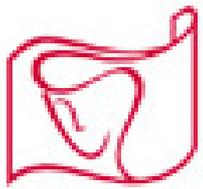




Answering Questions

- Prepare for questions
- Don't preface your answer
- Clarify
- Amplify
- Maintain your style
- Be honest

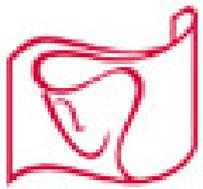




Answering Questions

Employ the 25% - 75% rule.
Keep answers to the point

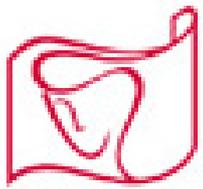




Networking

- People you know
- Friends
- Business acquaintances
- Organizations

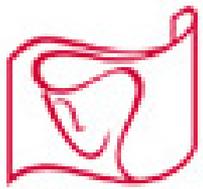




Personal Boundaries-Don'ts

- Give out your home phone number
- Attempt to answer medical questions
- Feel like you should counsel members of the audience

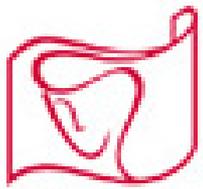




Networking

- Community organizations
- Community events
- Service organizations
- Health fairs
- Library

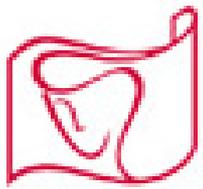




Networking

- Media
- Television
- Radio
- Newspaper

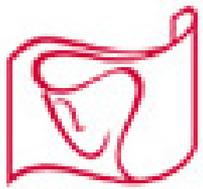




Steps to Conducting Your Presentation

- Sign in
- Welcome greeting
- Housekeeping issues
- Describe outline of the presentation

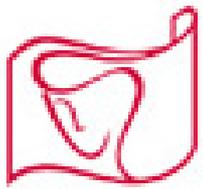




Steps to Conducting Your Presentation

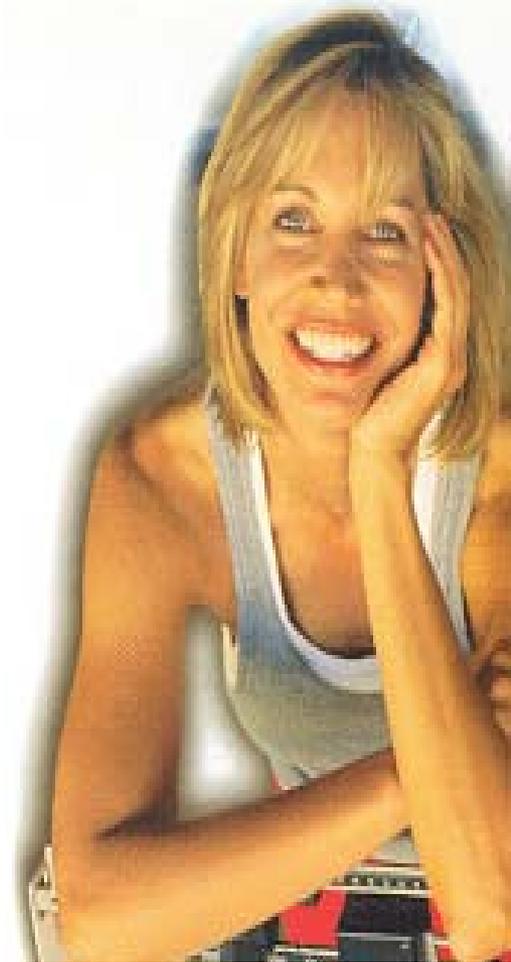
- State the prevalence of von Willebrand disease
- Explain the importance to you
- Deliver the “Woman Can Have Bleeding Disorders” presentation from the NHF Project Red Flag Toolkit
- Referral issues

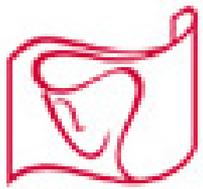




Steps to Conducting Your Presentation

- Questions from the audience
- Distribute handouts

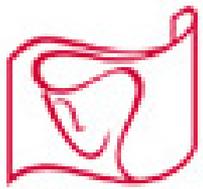




Personal Boundaries Do Set Limits

- Time
- Emotions
- Personal information





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





WOMAN-TO-WOMAN CURRICULUM

Appendix I

Community Contact Form Letter

Date:

Insert Organization/Business Name

Attn.: Insert Contact Name

Insert Street Address

Insert City, State, Zip Code

Dear: Insert Contact Name

The Insert Organization/Business Name has been identified by the Insert Chapter/Treatment Center Name as a possible venue for educating members of your community about bleeding disorders. It has been estimated that up to 2% of the Insert State Name female population, Insert 2% of female population in State women and girls, could be affected by a bleeding disorder called von Willebrand disease. Currently, only a small percent of those with bleeding disorders have been diagnosed and receive appropriate care. Therefore, thousands of women have bleeding symptoms that have not been diagnosed or have been misdiagnosed.

The Insert Chapter/Treatment Center Name and the members of your community have joined together to spread the important message that “Women Can Have Bleeding Disorders.” Through the Woman-to-Woman project peer educators affected by a bleeding disorder have been trained and provided with the necessary resources to bring this message to the Insert Organization/Business Name. *At no cost to you, we would like to provide an interactive 30-50 minute workshop for the women of the Insert Organization/Business Name.*

It is Insert Chapter/Treatment Center Name goal to heighten awareness about bleeding disorders and assure access to care for the Insert Organization/Business Name women. Please refer to the presentation outline enclosed for further details. Bringing this message to your organization’s members could mean dramatically improving the life of a woman or young girl who is needlessly suffering with bleeding symptoms due to lack of information. *If you’d like a member of your community to speak to your group or if you have questions about women and bleeding disorders please call Insert Chapter/Treatment Center Contact Person and Phone Number. Thank you for your cooperation.*

Sincerely,

Insert Chapter/Treatment Center Contact Person
Title

Insert Chapter/Treatment Center Contact Person



WOMAN-TO-WOMAN CURRICULUM

Woman Can Have Bleeding Disorders

Presented by a member of your community affected by a bleeding disorder.

- I. Welcome and Introduction
- II. The Signs and Symptoms of a Bleeding Disorder
- III. von Willebrand Disease
 - A. What is von Willebrand disease?
 - B. Who is affected by von Willebrand disease?
- IV. Personal Stories of Women affected by a Bleeding Disorder
- V. The Diagnosis of a Bleeding Disorder
- VI. The Treatment of a Bleeding Disorder
- VII. Community Resources
- VIII. Question and Answer Session
- IX. Closing

By the end of the presentation the audience should feel comfortable identifying bleeding disorders symptoms, and knowing what to do if they or someone they know suspect that they have a bleeding disorder.



WOMAN-TO-WOMAN CURRICULUM

Appendix J

Community Presentation

Date: _____

Group Name: _____

Contact Person: _____

Phone Number: _____

Attendance:

	Name:	Phone Number:	E-Mail:	Address:
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				



WOMAN-TO-WOMAN CURRICULUM

Appendix J (Continued)

9.				
10.				
11.				
12.				
13.				
14.				
15.				
16.				
17.				
18.				
19.				
20.				

Signature: _____



WOMAN-TO-WOMAN CURRICULUM

Appendix K

Community Group Registry Form

	Volunteer Name	Group Name	Presentation Date	Group Size	Delivered?	Notes:
1.					Y N	
					Y N	
					Y N	
					Y N	
2.					Y N	
					Y N	
					Y N	
					Y N	
3.					Y N	
					Y N	
					Y N	
					Y N	
4.					Y N	
					Y N	
					Y N	
					Y N	



WOMAN-TO-WOMAN CURRICULUM

Appendix L

Practice Presentation Sign-up

Presentation #1

Volunteer 1	Name: _____	Steps 1-5	10 minutes
Volunteer 2	Name: _____	Personal Story	5 minutes
Volunteer 3	Name: _____	Slides 1-6	5 minutes
Volunteer 4	Name: _____	Slides 7-12	10 minutes
Volunteer 5	Name: _____	Steps 8-11	5 minutes

Presentation #2

Volunteer 1	Name: _____	Steps 1-5	10 minutes
Volunteer 2	Name: _____	Personal Story	5 minutes
Volunteer 3	Name: _____	Slides 1-6	5 minutes
Volunteer 4	Name: _____	Slides 7-12	10 minutes
Volunteer 5	Name: _____	Steps 8-11	5 minutes



Project Red Flag
Real talk about women's bleeding disorders
 NATIONAL HEMOPHILIA FOUNDATION

WOMAN-TO-WOMAN CURRICULUM

Appendix M

Community Contact Thank You Form Letter

Date:

Insert Organization/Business Name

Attn.: *Insert Contact Name*

Insert Street Address

Insert City, State, Zip Code

Dear: *Insert Contact Name*

Thank you for providing an opportunity to discuss bleeding disorders in women. *Insert Organization/Business Name* supplied an excellent venue for educating members of the community about bleeding disorders. It has been estimated that up to 2% of the *Insert State Name* female population, *Insert 2% of female population in State* women and girls, could be affected by a bleeding disorder called von Willebrand disease. Currently, only a small percent of those with bleeding disorders have been diagnosed and receive appropriate care. Therefore, thousands of women have bleeding symptoms who have not been diagnosed or have been misdiagnosed.

As you know, the *Insert Chapter/Treatment Center Name* and the members of the bleeding disorders community have joined together to spread the important message that “Women Can Have Bleeding Disorders”. Through the Woman-to-Woman project, peer educators affected by a bleeding disorder have been provided with the necessary skills and resources to bring this message to the community. *We appreciate your allowing Insert Volunteer Name to share this important information with Insert Organization/Business Name.*

Sincerely,

Insert Chapter/Treatment Center Contact Person

Insert Chapter/Treatment Center Contact Person Title



Project Red Flag
Real talk about women's bleeding disorders
NATIONAL HEMOPHILIA FOUNDATION

WOMAN-TO-WOMAN CURRICULUM

Appendix N

Post-training Assessment:

- For answers to questions about bleeding disorders an individual can contact _____.
 - the local chapter (insert name)
 - their primary physician
 - a local hematologist
 - the local hemophilia treatment center (insert name)
 - the National Hemophilia Foundation
 - any of the above
- A bleeding disorder is a flaw in the body's blood coagulation system. T F
- Bleeding disorders are caused by a _____.
 - low level of clotting factors in the bloodstream
 - defect in the clotting factor in the bloodstream
 - defect in the platelets in the bloodstream
 - a and c
 - all of the above
- Of the several types of bleeding disorders which affects both men and women equally?
 - Hemophilia A
 - Christmas Disease
 - Factor IX deficiency
 - von Willebrand disease
- von Willebrand disease is the most common inherited bleeding disorder. T F
- von Willebrand disease is thought to affect as many as _____ of the population.
 - .5%
 - 7-10%
 - 1-2%
 - 12%
- von Willebrand disease is a genetic disorder. T F
- A genetic carrier of a bleeding disorder can have bleeding symptoms similar to an individual with a bleeding disorder. T F

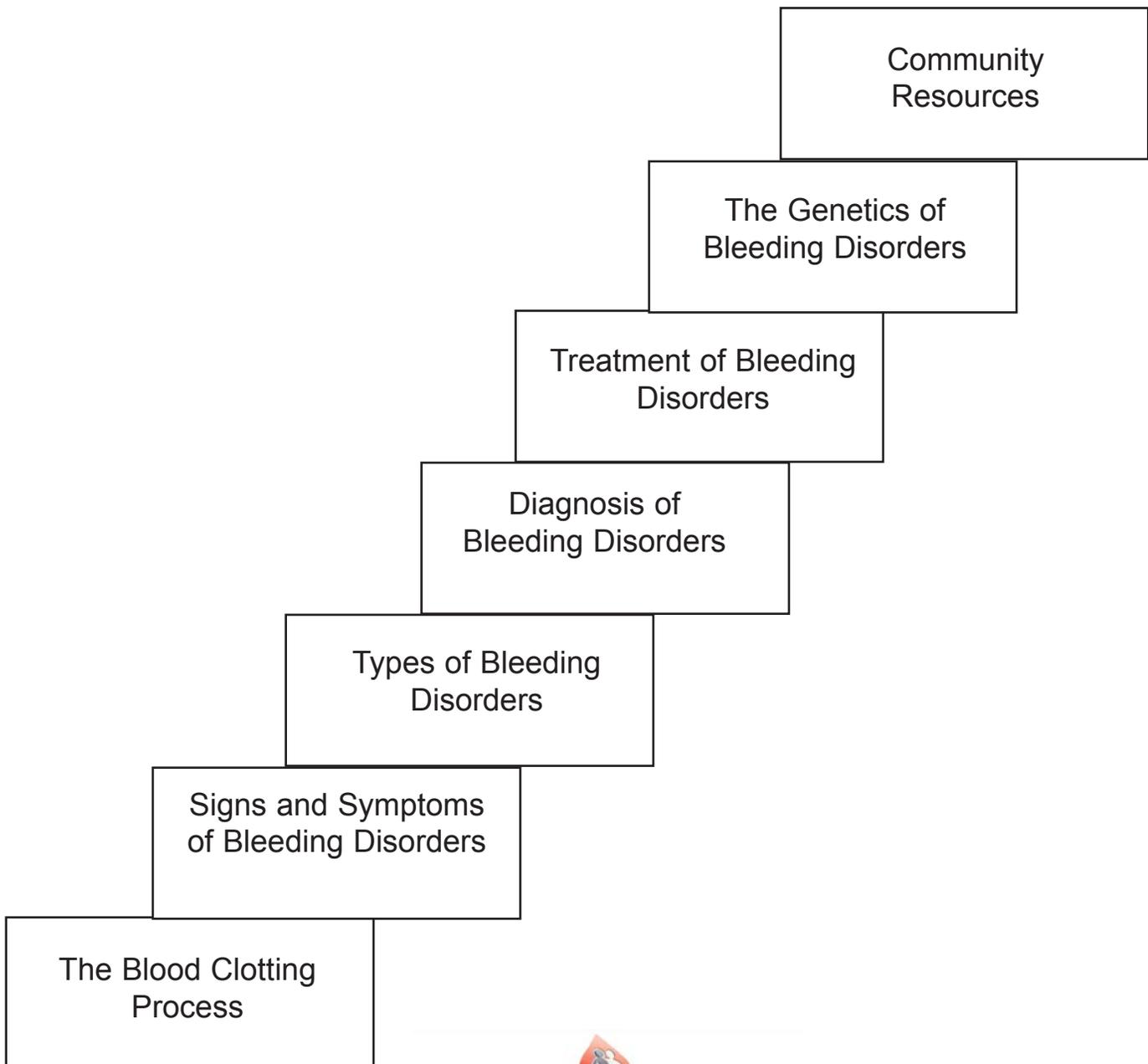
9. It is rare for a person with von Willebrand disease to have joint or muscle bleeds. T F
- 10 Specialized laboratory tests are part of the process in diagnosing a bleeding disorder. T F
- 11 A number of effective treatment options are available for women with bleeding disorders. T F



Project Red Flag
Real talk about women's bleeding disorders

APPENDIX O

Building Blocks to Identification and Treatment of Bleeding Disorders



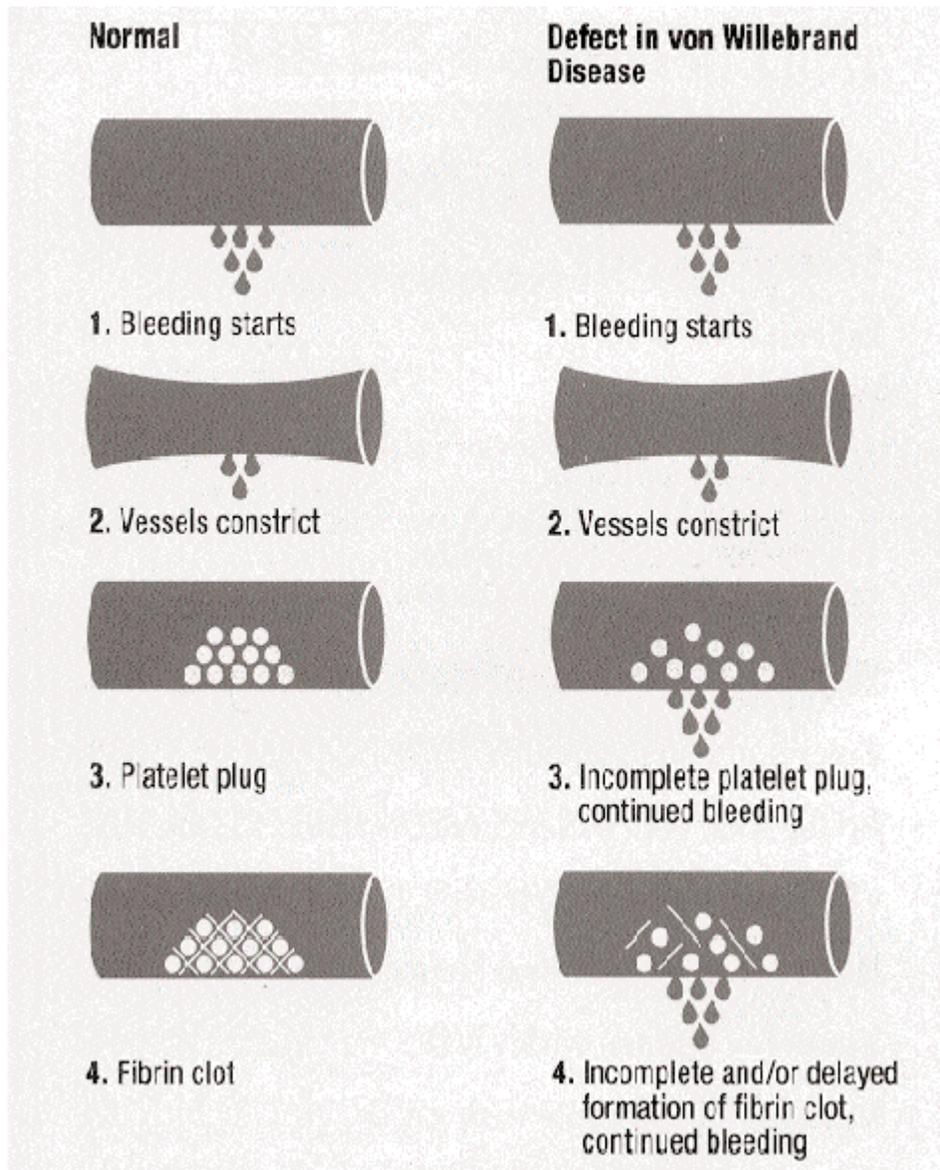
NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

APPENDIX P

The Process of Blood Clotting



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Project Red Flag
Real talk about women's bleeding disorders

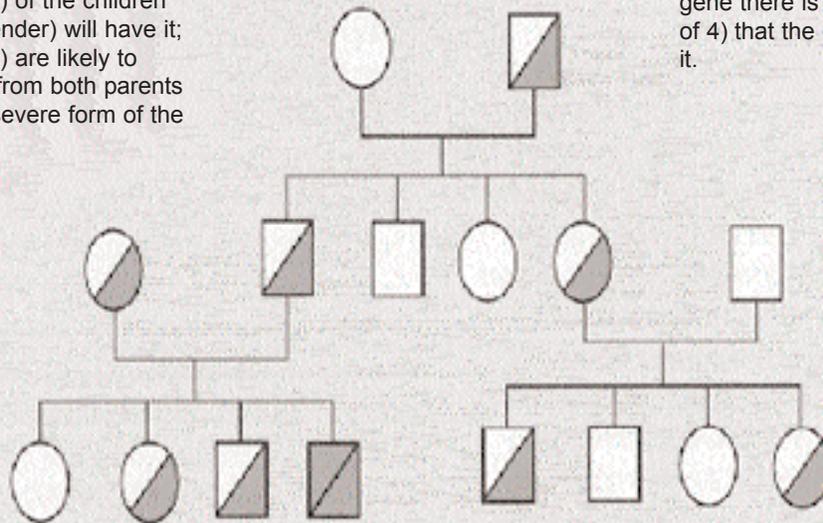
WOMAN-TO-WOMAN

APPENDIX Q

Inheritance Pattern in von Willebrand Disease

If both parents have an abnormal vW gene, the statistical likelihood is that 75 percent (3 of 4) of the children (irrespective of gender) will have it; 25 percent (1 of 4) are likely to inherit the defect from both parents and thus have a severe form of the disorder.

If one parent (regardless of gender) has an abnormal W gene there is a 50% chance (2 of 4) that the children will have it.



female	male	
		normal
		mild von Willebrand disease
		severe von Willebrand disease

Used with permission.
Adapted from Robert Montgomery, MD



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



WOMAN-TO-WOMAN CURRICULUM

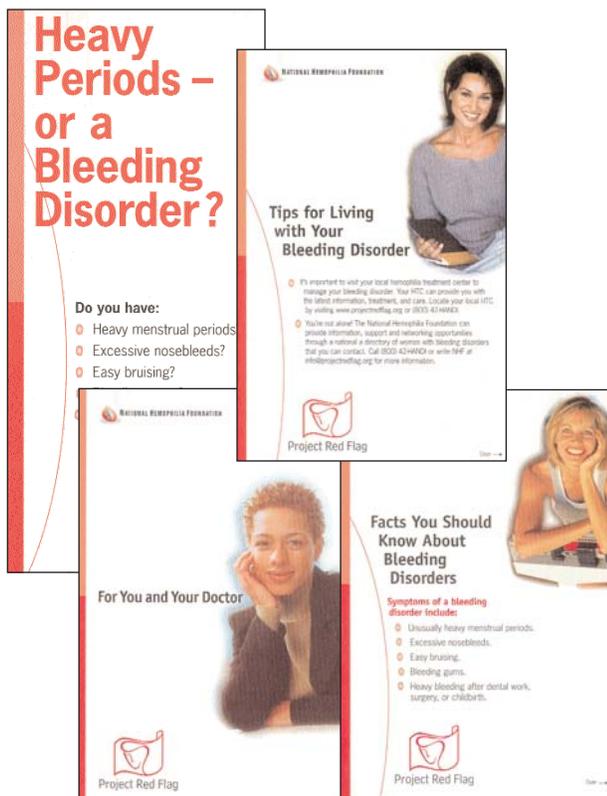
Appendix R

REFERENCES

1. Feiden, K. (1999, July). von Willebrand Disease: A Huge Undiagnosed Problem. Hemalog, pp. 10-13.
2. La Fon, Jill. (1995). Exploring von Willebrand Disease.
3. Maahs, Jennifer. (1999). Partners in Hemophilia Education Program. von Willebrand Disease, Electrophoretic Analysis of von Willebrand Factor.”
4. National Hemophilia Foundation. (1997). What You Should Know About Bleeding Disorders.
5. Ottum, Marilyn and Ziebell, Carrie. (1999). Teaching Master. “Providing Outreach to Women and girls through Education and Referral.”

ORDER FORM

Project Red Flag: Real Talk About Women's Bleeding Disorders



Heavy Periods or a Bleeding Disorder?

This handout raises awareness in women who have heavy periods and/or symptoms that may be caused by a bleeding disorder.

Tips for Living with Your Bleeding Disorder

This comprehensive handout gives valuable tips for women living with a bleeding disorder.

Facts You Should Know About Bleeding Disorders

A brochure that helps to educate you and your doctor about the importance of being tested for a bleeding disorder and the symptoms, testing and treatment of von Willebrand Disease.

For You And Your Doctor

This handout gives comprehensive facts about women's bleeding disorders such as von Willebrand disease (VWD) and sources for obtaining further information.

BROCHURES ARE NOW AVAILABLE IN SPANISH

Please send order forms to: National Hemophilia Foundation, Publication Orders, 116 West 32nd Street, 11th Floor, New York, New York 10001, (212) 328-3700 or (800) 42-HANDI, FAX (212) 328-3799

MAIL ORDER TO: (Please print information)

Name/NHF Membership ID# _____

Organization/Title _____

Address _____

City _____ State _____

Phone _____ Fax _____ E-mail _____

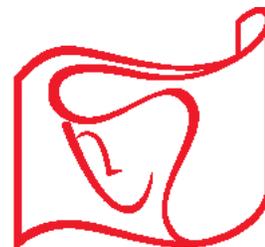
Please indicate quantities for each handout:

Heavy Periods Or A Bleeding Disorder _____ English _____ Spanish

Facts You Should Know About Bleeding Disorders _____ English _____ Spanish

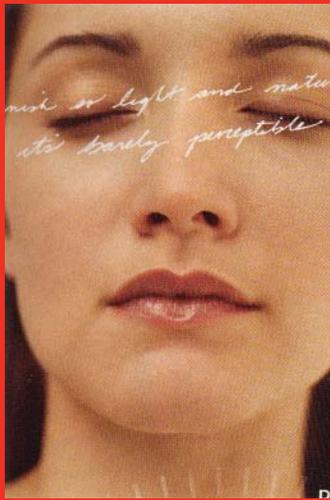
Tips For Living With Your Bleeding Disorder _____ English _____ Spanish

For You And Your Doctor _____ English _____ Spanish



Project Red Flag
Real talk about women's bleeding disorders





A DISCUSSION GROUP FOR WOMEN

on www.projectredflag.org



A brand new vehicle for networking and information exchange

The discussion group has been designed especially for women, girls and parents/guardians of female children affected by bleeding disorders. It is the place for them to ask questions, get appropriate information and responses, and to connect with people who share their interests and concerns. Visit the site today!

Project Red Flag: Real Talk About Women's Bleeding Disorders
in cooperation with

ZLB Behring

