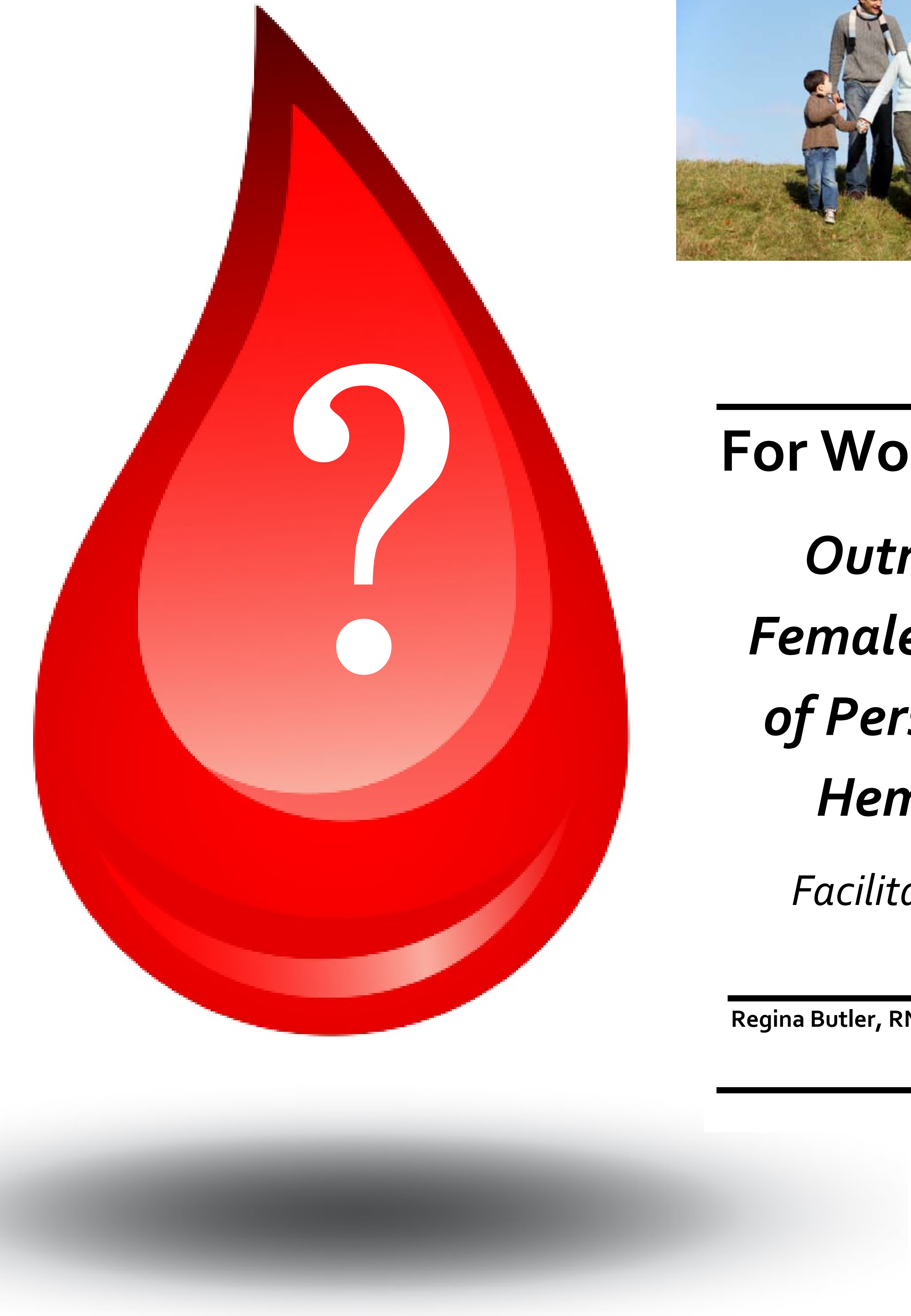

For Women Only:

Outreach To Female Relatives of Persons With Hemophilia

Facilitator's Guide

Regina Butler, RN

Danielle Deery, JD

FOR WOMEN ONLY:

OUTREACH TO FEMALE RELATIVES OF PERSONS WITH HEMOPHILIA

FACILITATOR GUIDE

Developed for The National Hemophilia Program Coordinating Center (NHPCC) for the Maternal Child Health Bureau for Federally Funded Hemophilia Treatment Centers

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July 2015™

TABLE OF CONTENTS

CURRICULUM OVERVIEW

Individuals with hemophilia who are served in federally funded hemophilia centers (HTCs) in the U.S. receive comprehensive care and have demonstrated better outcomes than those who receive care outside this system. The care is provided by multi-disciplinary teams of experts throughout the life course of the individual with hemophilia. However, some care providers have noted a lack of systematic identification of women and girls who may be carriers of hemophilia. In addition, materials and programs to provide these women with the information that they need to make informed decisions and to promote optimal health outcomes for themselves and for their children are not easily available.

This curriculum was developed to assist HTC staff in their efforts to provide important information to the female relatives of the HTC patients as well as a tested format for such education.

The theme of the curriculum is that female relatives of individuals with hemophilia deserve and need information to make informed decisions about their health, their future, family planning, and, most importantly, to enable them to advocate for information, testing and services to prevent complications for themselves and for their future children.

The facilitator guide has been developed to assist HTC staff in each step of the process of planning and implementing a program for female relatives of their patients. The guide includes recruitment information, registration templates, faculty recommendations, tips on room size and set up, materials needed, detailed notes, slides, and resources for presenting the material.

The Specific Goals of the Curriculum Are:

1. **To raise awareness of HTC staff of the need for outreach to female relatives of their patients with hemophilia.**
2. **To foster implementation of outreach/educational programs by HTCs through provision of a detailed curriculum.**
3. **To provide materials and resources for providers and women to facilitate advocacy for appropriate care before, during and after pregnancy**

The course is designed to be a hands-on, interactive half day or evening program facilitated by Hemophilia Treatment Center staff or their designees with knowledge and expertise in hemophilia, its genetics, current treatment and outlook for children born with hemophilia, and the risks and options available for women who may be carriers.

THE ROLE OF THE FACILITATOR

The role of the facilitator is to guide participants through the learning process by presenting concepts, explaining information, keeping the group on track and to assure that each important piece of information is discussed. As a facilitator, it is important to be prepared with the content and to gauge the audience to make adjustments in the plan as needed during the program.

In this program, several sections require participant feedback. That feedback will provide some of the answers and cover important information without a formal presentation on that content. However, it is the responsibility of the facilitator to prompt the audience or add important facts that do not arise.

Therefore, the guide has a list of possible answers that all should be discussed. If one or more of these are not elicited by audience responses, the facilitator will need to add that information and make sure that the topic is covered. For example: "Good discussion. What about daughters of men with hemophilia? They are definitely carriers since they inherit the only possible X from the father, the one that carries hemophilia". Then, the recorder will add that to the list of responses on the flip chart.

METHOD OF DELIVERY

This curriculum was designed to be presented in a varied format and attempted to avoid the traditional medical model of a series of lectures or "talks". The methods used in the pilot programs included power point presentations which were presented informally, guided discussions, and case studies.

USING THE FACILITATOR GUIDE

The content in this guide and the accompanying materials and slides provide the foundation for the course. It is important that the facilitators be prepared to use their own clinical experience and knowledge to elaborate on specific topics to best present the information in a comprehensive manner.

The facilitator will need to use his or her own words in presenting the material in this guide and will need to plan, with other team members, when and how to adjust the timing or methods of presentations to meet the particular needs of an individual group of learners.

SIZE OF AUDIENCE AND TIMING OF THE SESSIONS

The material in this curriculum is best presented to a group of 15-25 women to allow for participation and sharing of experiences and questions. If the audience is expected to be more than 20 women, the times allotted for responses and discussion may need to be expanded. So, consider the audience size when planning exact timing of the program and its segments.

ROOM REQUIREMENTS

The ideal room arrangement for the program is to have half round tables for groups of women, with all facing front, or to arrange the room in a U shape configuration of long tables. Allow room for handouts, note taking and eating, if meals or refreshments are in your plan. The participants will be more comfortable with good spacing of chairs.

Rooms should be equipped with a computer and projector, a screen visible to all participants, an easel with a newsprint flip chart and colored markers. A big bowl for the fishbowl with at least 50 note cards and 20 pencils or pens will be needed for the fishbowl.

OTHER EQUIPMENT NEEDED

Two bingo cages with 20 red balls, 10 white balls and 20 blue balls will be needed for the genetics exercises. If not available, the same exercise can be done with two opaque boxes with squares or some symbol to represent eggs and sperm in the same colors as above. The balls or squares need to be marked as described in the exercise.

HANDOUTS

Participant handouts can be placed in folders or binders. They should include copies of the slides and notes pages, HTC contact information for local HTCs, genetic testing information, the NHF Inheritance Brochure, the Children's Hospital of Philadelphia HTC Genetic Testing Booklet, and other local materials thought helpful. Pens for notes should also be included.

See Appendix A for the handouts

PREPARATION FOR THE PROGRAM

Local planners will decide on date, time, location, audience, facilitators and methods of recruitment. The program was developed for women 18 and over, but was adapted for girls 16 and over if accompanied by a female parent or guardian.

RECRUITMENT MATERIALS

When planning recruitment, it is helpful to consider how to ensure that the audience members are able to participate, contribute, learn and promote a positive learning environment for the other participants. In that light, the curriculum developers decided that, for the pilots, the recruitment would be through HTCs with support and marketing from consumer groups, such as NHF Chapters. Therefore, each participant was registered through the HTC of their relative with hemophilia. In the event that the woman learned of the program through marketing and was not associated with an HTC, contact information for one of the planners was provided on the flyer so that the planning committee could complete the screening in lieu of an HTC. In general, HTCs received letters asking them to invite female relatives that they know and to ask their male patients to share the information with their female relatives. When recruitment was slow, the HTC staff reached out to patients or relatives that they thought would benefit from the program.

REGISTRATION

Registration is best completed by the HTC staff known to the participant or by the planning committee as above. ***See Appendix B, C, D & E for the Outreach Invitation Letter, Outreach Flyer, Acceptance Letter Examples and Family History Questionnaire.***

Once registered, an acceptance letter with further meeting details, including exact location and directions, is mailed to the participant.

FAMILY HISTORY SURVEY

Each registered participant receives a Family History Survey and is asked to complete it before the program and return it (by mail, email or fax) to a designated planning committee member. The Family History Survey is reviewed and a pedigree is developed for each participant. Upon arrival at the program, each participant receives their individualized family pedigree. If available, the pedigree can be electronic (such as through Progeny ***See Appendix F*** for pedigree sample), but hand drawn pedigrees are fine.

Note: *Some participants do not return the survey. Planners may decide to accept them on site and mail the individualized pedigrees to the participants after the program.*

PRE AND POST TESTS

Pre and post tests are included in this guide for two reasons:

1. Pre-test results assist facilitator planning to ensure that incorrect information or missed questions are clearly clarified during the program.
2. Comparison of pre and post test results help evaluate the effectiveness of the program and guide needed revisions.

Pre-tests can be completed by participants during the registration/ gathering time of the program and can be scanned by presenters to drive needed emphasis in content. Sufficient time should be allotted for registration and pre-test before the formal introductions. ***See Appendix G for the Pre Test***

FLIP CHART USES & TIPS

Have a facilitator write on the flip chart located in the front of the room

Group similar responses together. Do this either by dividing up the sheet into sections or use different colored markers for each topic.

Save the list to refer back at the end of the program to make sure that their needs were met and topics they wanted were covered.

FISHBOWL/PARKING LOT/FLIP CHART

Fishbowl – Used for participants to drop in questions, comments concerns throughout the meeting as to not interrupt the flow of the meeting. Index cards and any glass bowl, hat, box, etc…will do.

Parking Lot – Questions are placed in the "Parking Lot" when they are questions that will produce side tangents and derail the flow of the presentation. These can be written on a separate page on the Flip Chart.

Flip Chart – Used thought out the presentation---Multi colored markers are helpful

EVALUATIONS

As for all educational programs, participant evaluations are necessary to document the success of the program and, more importantly, to assist planners in making needed changes to the curriculum, room, time, etc. A sample evaluation tool is included in this facilitator guide. ***See Appendix H for the evaluations***

PROGRAM CONTENT

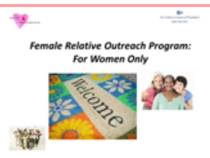
SCHEDULE	FACILITATOR NOTES/ MATERIALS
Suggested schedule and slides will be noted on the left hand side	Notes and materials will be noted on the right hand side and outlined in the grey boxes

REGISTRATION AND PRE-TEST: 15- 30 MINUTES

Meal: 15 – 45 Minutes	Start at registration and can be adjusted longer or shorter depending on total time available.

SESSION 1: INTRODUCTION 25-30 MINUTES

SLIDES 1-2



Female Relative Outreach Program:
For Women Only

Introductions

Requires: Flip chart, fish bowl, pencils, markers, note cards.

Introduction of Staff	Introduce each member of your staff, their hemophilia treatment center role and their role in the program.
Introduction of Participants	Ask participants to give their names and give one sentence about themselves
"Why are you here?"	Ask for volunteers and ask why they decided to attend Depending on time – may ask for one or two volunteers or elect more volunteers.

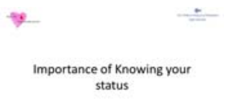
	Recorder to use flip charts with colors to group similar responses (i.e. "find out if I am a carrier", "See out who in my family can be a carrier", etc. in red.)
	Ask, "Did any of you come because you think it may be important to your own health?
"Why are you here?" contd.	**If responses do not include the following, suggest them, if they do not include them, reinforce them:**
	My own health Planning for safe labor and delivery Health of babies Information for other relatives, such as my daughters Information for other relatives Family planning
Introduction to Program and Purpose of the event	Do not answer questions here
Introduce fish bowl	Bowl, cards, pencils introduced to group Display in room and let them know that they can write any questions that they have that weren't addressed and we will answer each of them at the end

Introduce Parking Lot

Point out flip chart page with title "Parking Lot". Explain that the facilitators will put topics in the parking lot that arise during discussion but can't be addressed immediately. They will be answered at the end of the program.

SESSION 2: IMPORTANCE OF KNOWING CARRIER STATUS 20 MINUTES

SLIDES 3-5



Importance of Knowing your status

Importance of Knowing your status

Implications for you
- Medical management
- Avoid health complications
- Family planning

Implications for family members
- Your status may provide information for daughters, sisters, cousins and other relatives at risk
- Health complications for future generations may be avoided by knowing and planning

Judy K.
- 27 years old
- Mother's brother has hemophilia
- Never had carrier testing
- Never had surgery or teeth extracted
- Was not recommended to HTC before or during pregnancy
- Delivered healthy 6 lbs. 4 oz. baby girl
- Bled significantly after delivery
- Required several red cell transfusions
- Required major surgery to stop bleeding

This session is intended to engage, grab their attention and help them know why they should pay attention to the program.

Implications for you (case example)

Medical management and treatment may be indicated

Health complications may be avoidable

Family planning options may be available

Implications for family members (case examples)

Your status can provide information to help other relatives' risks

Health complications in future generations may be avoidable

SESSION 3: HEMOPHILIA IN 2015 — 30 MINUTES

SLIDES 6-26

Requires: Flip chart, markers, tape

Current clinical picture for males with hemophilia

Ask how care and outcomes <u>have changed</u>

Interactive discussion using flip chart

Recorder captures responses

***Expected responses**: (If not raised by participants, facilitator to suggest)*

No or minimal joint disease

Decreased viral infections

Prophylaxis

More active lifestyle

Safer products

Prolonged half-life products

Comprehensive care

Care and treatment and outcomes

Compare and contrast care and outcomes for babies born today with what was expected in previous generations. Emphasize that their experiences with older relatives may give them a picture of hemophilia that is no longer accurate in 2015.

Implications for women who may be carriers

"What's in it for you"?

Care and treatment

Common symptoms for carriers

Medical implications

Case examples –

Possible management/considerations for:

Surgical procedure in carrier

L&D in carrier

At risk newborn male

BREAK

SESSION 4: INHERITANCE PATTERNS 40 MINUTES


Being a carrier can affect your children……


- Full term male born in community hospital
- Prolonged labor
- Vacuum extraction
- Presented with sub-dural bleeding
- Retrospective family history reveals strong maternal family history of factor VIII deficiency
- Maternal grandfather affected
- Mother unaware of her carrier status

Sam G.


William B.

- Full term male
- Uncomplicated vaginal delivery
- Extensive bleeding after circumcision
- PTT prolonged
- Moderate Factor VIII deficiency diagnosed
- Retrospective family history reveals maternal great uncles with hemophilia


…Being a carrier can affect your health too!

SLIDES 27-30

Requires: Bingo balls and cages/ boxes and Genetic lottery activity cards

X Linked Inheritance

Instructions for Genetic Bingo Activity found in *Appendix I*

Pedigrees

Copies of individual and sample pedigrees

Distribute pedigrees

	Use interactive pedigree to educate on pedigree nomenclature
Obligate vs. potential carriers	You are a carrier if…You may be a carrier if…..
	Give examples using pedigree
Discuss results of pedigree survey	Are you a carrier: Yes, No, Unsure
	OK to be unsure, sometimes requires testing HTC can still support you, even if not sure or untested. You may have learned that carrier testing is not needed if, for example, your father has or had hemophilia or you have a son and a brother with hemophilia.
	If you are an obligate carrier, you may want to be seen at an HTC and seek factor level testing to see if you are at risk for abnormal bleeding
Severity remains the same within a family	Some women may worry that their relative has mild hemophilia and think their son may have severe; others may hope that even though severe hemophilia runs in their family, that their child may have mild hemophilia. It is important to emphasize that the severity is carried on the gene and does not differ among members of the same family. However, phenotypes can vary and every family member may have different symptoms.

SESSION 5: GENETIC TESTING VS FACTOR LEVELS 10 MINUTES

SLIDES: 31-42

Overview of each test

Genetic Testing	Emphasize difference between genetic testing and factor activity levels and uses of each test.: Genetic testing for carrier determination Factor levels for bleeding risk assessment Using slides as a guide, include that there are benefits to genetic testing for the health of the female. That some women have lower levels of factor VIII or factor IX and can be at risk of bleeding. Factor levels do address that question and may be done to assess bleeding risk in potential carriers but do NOT assess carrier status. In the experience of the authors, a real risk is that a normal factor level may be taken as evidence of non-carrier status by the woman, girl, or parents of the girl tested. Of course, this is not accurate and has led to unexpected delivery of affected males with no preparation or precautions taken.
Importance of starting with affected male	Ease of identification of carrier and reduced cost.
Cost/ insurance	Provide actual examples of costs of common genetic testing for hemophilia, highlighting relatively low cost for carrier testing when familial mutation is identified.

Access: My Life, Our Future	My Life, Our Future (MLOF) brochures found in ***Appendix K.***

SESSION 6: WRAP UP — 10 MINUTES

Refer to initial reasons for attending	Point out flipchart from initial responses; make sure they are all addressed. "This is why you told us that you decided to come today…as you can see, we did cover this and this and etc… Is there anything that you are taking away that you may not have thought of or that you want to add?

FISHBOWL/PARKING LOT — 20 MINUTES

Review all questions, make sure that everybody has what they need

Fishbowl	Refer to fishbowl –address all questions that were placed in it
Parking Lot	Refer to parking lot – If any topics are still outstanding address to the group and/or offer individual follow-up discussion.

EVALUATIONS AND POST-TEST — 15 MINUTES

Evaluations	***See Appendix H for the Evaluations***
Post Test	***See Appendix I for the Post test***

APPENDIX A: HANDOUTS

Index of Handouts for Attendees:

1. Presentation Slides

2. Care Matters, Family Newsletter from the Comprehensive Hemostasis and Thrombosis Center at the Children's Hospital of Philadelphia, Summer 2013, "The Importance of Genetic Testing," by Regina Butler, RN

3. Hemophilia/von Willebrand Disease (VWD) Emergency Treatment Guidelines Wallet Card developed by the Mid-Atlantic Region III Executive Committee.

4. "Caring for your Child with Hemophilia," National Hemophilia Foundation

5. "What you Need to Know: Hemophilia and Genetic Testing," The Children's Hospital of Philadelphia, Division of Hematology, 2014.

6. MASAC Guidelines for Perinatal Management of Women with Bleeding Disorders and Carriers of Hemophilia A and B, #192, 2009 (included a summary sheet by Kay Miller, RN)

7. Resources for Families with Hemophilia (specific to the Pennsylvania area)

8. "Knowledge is Power for Symptomatic Carriers," by Stephanie Stephens, HemAware, June 25, 2010.

9. "Test Takers," by Heather Boerner, HewAware, October 24, 2011.

Resources for HTCs:

1. MLOF Brochure
2. Evaluation
3. Pre-test and Post-Test
4. FRUIT tool

APPENDIX B: FEMALE OUTREACH LETTER EXAMPLE

__________, 2015

Dear patients and families:

We are writing to ask your help in reaching out to women in your family who are or may be hemophilia carriers to let them know about an exciting new program in the Philadelphia area.

Many women and girls are unaware of their hemophilia carrier status which may lead to significant negative complications to their own health or that of their children. We have an important program planned for women in families with hemophilia to help promote their health and to reduce complications related to hemophilia in future generations of your family.

This program, "***For Women Only- Your Hemophilia Carrier Status: Implications for You and Your Family"***, is designed for women 18 and older. It will be held in **Philadelphia on Thursday evening, October__, 201__ from 5:30 – 9 PM.** Dinner and parking will be provided.

Topics will focus on the importance of knowing carrier status, inheritance patterns, genetic testing, and care and treatment. Participants will have the chance to receive their own family tree through an electronic program.

In order for your family members to have the opportunity to participate, ***please pass this letter and the enclosed flyer to all of your female relatives.*** Ask them to call your Hemophilia Treatment Center by August 12, 2014 to apply. Applications must be completed by the HTC staff and be submitted to us by August 15, 2014. Women who are accepted for the program will be notified by August 22, 2014. More specific details and location will be provided at that time and final plans made for their participation.

We look forward to meeting your family members.

Thank you very much for your help and your investment in the health of your family.

Please call _______________ at XXX-XXX-XXXX with additional questions.

Sincerely,

The ________________________ Women's Hemophilia Outreach Planning Committee

_____________________ _____________________ _____________________ _____________________

APPENDIX C: FEMALE OUTREACH FLYER EXAMPLE

The Pennsylvania Women's Hemophilia Outreach Planning Committee would like to invite you to:

For Women Only - Your Hemophilia Carrier Status: Implications for You and Your Family

This is a discussion and education event for female relatives ages 18 and up of patients with Hemophilia A or B. Topics will focus on the importance of knowing carrier status, inheritance patterns, genetic testing, and care and treatment. Participants will have the chance to receive their own family tree through an electronic program.

Location: Philadelphia, PA
Date: Thursday, October 2nd, 2014
Time: 5:30-9pm
Dinner and Parking will be provided

Please call your Hemophilia Treatment Center by August 12, 2014 to apply. Applications will be completed by the HTC staff at your center. Women who are accepted for the program will be notified by August 22, 2014.

We look forward to meeting you and your family members!

APPENDIX D: ACCEPTANCE LETTER EXAMPLE

August___, 2015

Dear _________________

We are pleased to accept your registration to the Female relative Outreach Program on

October ___, 2015 5:30 – 9:00 PM

The__________ Hotel

________________________ Ave, *City, State Zip Code*

Parking will be provided. Bring your ticket to the meeting registration table for validation.

As we intend to personalize the program to meet your needs, please remember that this event requires registration, so if you have other women in your family who would like to come, they will need to call their HTC to register right away.

IMPORTANT: In order to provide you with your personalized family tree, we will need you to please complete the attached survey as much as you can and return it in the enclosed addressed, stamped envelope by September 12. You can also email it back to John Smith at Smith@xyz.com ***or fax it to her at (xxx) xxx-xxxx.***

If you need help completing the survey, please call your HTC for help.

We will be serving dinner at the program. If you have any dietary restrictions, it is important that you call John Smith at (xxx) xxx-xxxx--- by September 12, 2014.

Since we are reserving space and ordering dinner for you, we ask that you kindly let us know as soon as possible if, for some reason, you are unable to attend.

We are looking forward to an interesting and informative evening.

See you on October _______!

The Planning Committee

APPENDIX E: FAMILY HISTORY QUESTIONNAIRE

Your Carrier Status: Implications for You and Your Family

FAMILY HISTORY QUESTIONNAIRE Your Name: ☐

Please complete this form to the best of your knowledge with **blood relatives only**. This will help us understand your family history. ***Use the blank page at the end for additional relatives.***

You

Age	# of Children		Diagnosis in your family	Your Carrier Status
	Male	Female		
			☐ Hemophilia A ☐ Hemophilia B ☐ Unsure	☐ Obligate carrier ☐ Known carrier by genetic testing ☐ Assumed carrier by factor level ☐ Non-carrier by genetic testing ☐ Unsure

Your Children (biological only)

First Name	Sex M/F	Age	Living Y/N	H= Hemophilia C= Female Carrier U= Unknown	Father's Name

Your Brothers and Sisters (biological only)

First Name	Sex M/F	Age	Living Y/N	H= Hemophilia C= Carrier U= Unknown	Mother's Name	Father's Name

Your Nieces and Nephews (biological only)

First Name	Sex M/F	Age	Living Y/N	H= Hemophilia C= Carrier U= Unknown	Mother's Name	Father's Name

Your Mother

Name	Age	Living Y/N	# of Children		C= Carrier U = Unknown
			Male	Female	

Your Mother's Parents (Maternal Grandparents)

First Name	Age	Living Y/N	# of Children		H= Hemophilia C= Carrier U= Unknown
			Male	Female	

Your Mother’s Brothers and Sisters (Your biological Maternal Aunts and Uncles)

First Name	Sex M/F	Age	Living Y/N	# of Children		H= Hemophilia C= Carrier U= Unknown	Mother’s Name	Father’s Name
				Male	Female			

Your Father

Name	Age	Living Y/N	# of Children		H = Hemophilia U = Unknown
			Male	Female	

Your Father’s Parents (Paternal Grandparents)

First Name	Age	Living Y/N	# of Children		H= Hemophilia C= Carrier U= Unknown
			Male	Female	

Your Father’s Brothers and Sisters (Paternal biological Aunts and Uncles)

First Name	Sex M/F	Age	Living Y/N	# of Children		H= Hemophilia C= Carrier U = Unknown	Mother’s Name	Father’s Name
				Male	Female			

Other relatives who have hemophilia or children with hemophilia

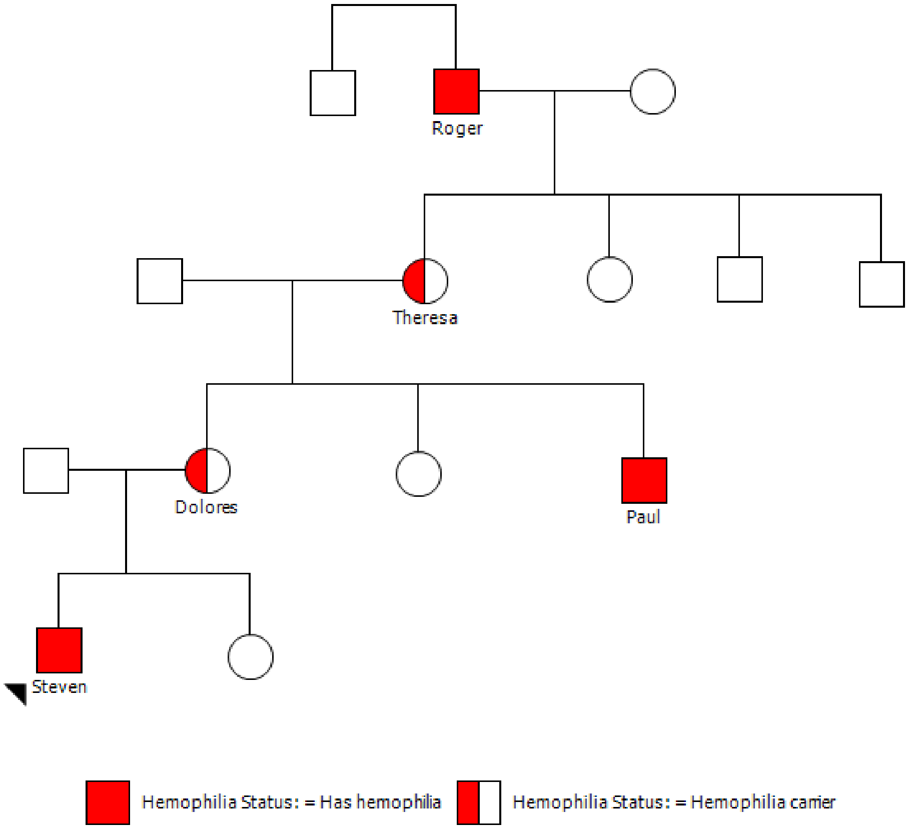
First Name	Relationship to You	Sex M/F	Age	Living Y/N	H= Hemophilia C= Carrier	Mother's Name	Father's Name

Please enter names of additional relatives that do not fit on the previous pages

First Name	Relationship to You	Sex M/F	Age	Living Y/N	H= Hemophilia C= Carrier U = Unknown

Additional Comments:

APPENDIX F: PEDIGREE



"For Women Only" Pre-Test

Attendee: _________

Date: ___________

1. Name the two types of hemophilia:

   ______________________ and ________________________

2. The most common site of bleeding in people with hemophilia is: (check one answer)
   a. Bleeding into the head
   b. Nose bleeding
   c. Joint bleeding
   d. Spinal cord bleeding

3. List two ways that advances in care over the past decades have improved outcomes for people with hemophilia.

   ____________________________ and

   ____

4. The severity of hemophilia from one generation in a family to another: (Circle one answer)
   a. Gets less severe
   b. Stays the same
   c. Can get more or less severe
   d. Gets more severe

5. A female is a carrier of hemophilia if: (Circle the BEST answer)
   a. Her father has hemophilia
   b. She has at least 2 children who have hemophilia
   c. She has 1 child who has hemophilia and at least 1 other relative who has hemophilia
   d. Any of the above
   e. None of the above

6. If a female is a carrier of hemophilia, what are the odds of her children either having hemophilia or being a carrier? (Circle all that apply answer)
    a. 100% of her daughters will be carriers
    b. 50% of her daughters will be carriers
    c. 100% of her sons will have hemophilia
    d. 50% of her sons will have hemophilia

7. Factor levels are the best way to tell if a woman is a carrier.

____ True ____ False ____ Not Sure

8. Symptoms that a carrier of hemophilia may experience include: (Circle all that apply)
    a. Heavy or long menstrual periods
    b. Bleeding after procedures or surgeries
    c. Abnormal bruising
    d. Bleeding after delivery
    e. No symptoms
    f. A combination of any of the above

APPENDIX H: EVALUATION EXAMPLE

Thank you for attending the education program, “For Women Only: Your Hemophilia Carrier Status: Implications for You and Your Family” on February 28, 2015. We would greatly appreciate your feedback on this program and ask that you take a few minutes to respond to the following questions:

For each item, please circle the response that most closely reflects your opinion:

1. Overall, how would you rate this program: Very Good Good Fair Poor

Comments:

Please rate the following topics:

2. Hemophilia overview and current care Very Good Good Fair Poor

Comments:

3. Importance of knowing your carrier status Very Good Good Fair Poor

Comments:

4. How hemophilia is inherited Very Good Good Fair Poor

Comments:

5. Genetic testing Very Good Good Fair Poor

Comments:

FOLLOW-UP BASED ON THE PROGRAM:

6. After the program, do you have a better understanding of how hemophilia is inherited?

Better   Same   Worse   Not Sure

7. After the program, are you going to obtain genetic testing for yourself?

Definitely   More Likely   Less Likely   Not Sure   Carrier status known

Why or Why Not? ____

8. After the program, do you have other female relatives who you will talk to about carrier risks?

Definitely   More Likely   Less Likely   Not Sure

Why or Why Not? ________________________ Who? __________________________

Please Evaluate the Following:

9. The program offered a good mix of formal information and discussion.

Strongly Agree   Agree   Disagree   Strongly Disagree

10. I would recommend this program to other female relatives.

Strongly Agree   Agree   Disagree   Strongly Disagree

11. I now have a better understanding of Hemophilia and current treatment

Strongly Agree Agree Disagree Strongly Disagree

12. This program gave me knowledge that I will use in planning healthcare for myself or my family

Strongly Agree Agree Disagree Strongly Disagree

13. What topics were the most helpful?

14. What topics were the least helpful?

15. Please rate the course in the following categories (check one response in each column).

Organization	Length	Content
____ Organized too rigidly	____ Too long	____ Covered too much
____ Well organized	____ Just right	____ Covered just enough
____ Disorganized	____ Too short	____ Covered too little
		_____ Too complex
		_____ Too simple

Please rate the following by circling your choice:

Meeting room set-up	Very Good	Good	Fair	Poor
Audiovisual materials	Very Good	Good	Fair	Poor
Participant handouts	Very Good	Good	Fair	Poor

16. Additional comments, suggestions, praises or criticisms:

APPENDIX I: POST TEST EXAMPLE

"For Women Only" Post-Test

Attendee: __________

Date: ____________

1. Name the two types of hemophilia:

_______________________ and _________________________

2. The most common site of bleeding in people with hemophilia is: (check one answer)
    a. Bleeding into the head
    b. Nose bleeding
    c. Joint bleeding
    d. Spinal cord bleeding

3. List two ways that advances in care over the past decades have improved outcomes for people with hemophilia.

_____________________________ and

____

4. The severity of hemophilia from one generation in a family to another: (Circle one answer)
    e. Gets less severe
    f. Stays the same
    g. Can get more or less severe
    h. Gets more severe

5. A female is a carrier of hemophilia if: (Circle the BEST answer)
    a. Her father has hemophilia
    b. She has at least 2 children who have hemophilia
    c. She has 1 child who has hemophilia and at least 1 other relative who has hemophilia
    d. Any of the above
    e. None of the above

6. If a female is a carrier of hemophilia, what are the odds of her children either having hemophilia or being a carrier? (Circle all that apply answer)
    a. 100% of her daughters will be carriers
    b. 50% of her daughters will be carriers
    c. 100% of her sons will have hemophilia
    d. 50% of her sons will have hemophilia

7. Factor levels are the best way to tell if a woman is a carrier.
   ____ True ____ False ____ Not Sure

8. Symptoms that a carrier of hemophilia may experience include: (Circle all that apply)
   a. Heavy or long menstrual periods
   b. Bleeding after procedures or surgeries
   c. Abnormal bruising
   d. Bleeding after delivery
   e. No symptoms
   f. A combination of any of the above

APPENDIX J: GENETIC BINGO LOTTERY INSTRUCTIONS

Option A: Using Bingo cages and balls:

1. Place equal numbers of white balls (represent unaffected "X") and red (represent affected "X") in one cage for "Mother"

Place equal number of white (Unaffected "X) and blue

(Normal "Y") in second cage for "Father".

2. Ask for volunteers to represent mother and father.
3. Ask volunteers to spin cages at the same time and see what combination of ping pong balls spill out:
   a. White and White = unaffected girl
   b. White and Blue = Unaffected boy
   c. White and Red = Carrier girl
   d. Red and Blue = Boy with hemophilia
4. Depending on available time, may change "parents" by changing colors of balls to represent father with hemophilia and unaffected mother or any combination to depict genetics of hemophilia.

Option B: May use red, white and blue index cards in an opaque box or container and simulate activity with reaching in to retrieve a card without looking.

APPENDIX K: MY LIFE OUR FUTURE BROCHURE

Where is *My Life, Our Future* available?

My Life, Our Future was initially rolled out to eleven HTCs as part of a pilot program to ensure all processes ran smoothly. During the four-month period, more than 130 people with hemophilia enrolled in the program, with more than 90% opting to participate in the research repository. Thank you to the participants and the pilot sites who helped us refine the program ahead of national rollout:

- University of Michigan Hemophilia and Coagulation Disorders, Ann Arbor, MI
- Emory / Children's Healthcare of Atlanta Comprehensive Hemophilia Program, Atlanta, GA
- Palmetto Health, Columbia, SC
- The Pennsylvania State University and The Milton S. Hershey Medical Center, Hershey, PA
- The Gulf States Hemophilia and Thrombophilia Center, Houston, TX
- Indiana Hemophilia & Thrombosis Center, Indianapolis, IN
- Center for Comprehensive Care & Diagnosis of Inherited Blood Disorders, Orange, CA
- Bleeding and Clotting Disorders Institute, Peoria, IL
- Arizona Hemophilia and Thrombosis Center at Phoenix Children's Hospital, Phoenix, AZ
- Hemophilia Center of Western Pennsylvania, Pittsburgh, PA
- Puget Sound Blood Center, Seattle, WA

Following the successful pilot, the program is now welcoming all interested HTCs across the U.S. to participate. To find out if your HTC is participating in the program, visit mylifeourfuture.org.

mylife ourfuture
Genotyping for Progress in Hemophilia

united in progress: the founders

athn
National Hemophilia Foundation
Puget Sound Blood Center
blood services | medicine | research
biogen idec
HEMOPHILIA

For more information, please visit:

mylifeourfuture.org

mylife ourfuture
Genotyping for Progress in Hemophilia

For years, the hemophilia community has waited for life-changing advancements and the promise of revolutionary science. The time has come to make these goals a reality.

My Life, Our Future is a nationwide campaign for progress in hemophilia. Leaders in our community have come together to offer a free genotyping test, so that you may gain a deeper understanding of your hemophilia today, while helping to advance the breakthrough treatments of tomorrow.

How will my participation support research?

For those participants who choose to contribute, data will be added to the ATHNdataset and samples securely stored at Puget Sound Blood Center (PSBC). In the future, scientists and researchers will be able to apply for access to support research projects designed to advance hemophilia care and treatment.

How will you ensure my privacy if I choose to support research efforts?

We will never provide your name or other identifying information to American Thrombosis and Hemostasis Network (ATHN) or to researchers, and will strictly guard the confidentiality of all participants. ATHN will secure all data via state-of-the-art technology consistent with current best practices, as well as state and federal laws designed to protect the privacy of patients.

Will Biogen Idec Hemophilia have access to my data?

No, Biogen Idec Hemophilia will not have special access to data or samples. In the future, along with researchers from academic institutions and other companies, Biogen Idec Hemophilia will have an equal opportunity to apply for access to the de-identified information through ATHN to support scientifically-sound research programs designed to advance hemophilia care.

My Life, Our Future: How it works

Genotyping begins with a simple blood test at your participating Hemophilia Treatment Center (HTC).

The sample is sent to PSBC for genetic testing and analysis.

A summary report is given to your HTC to be shared with you by your healthcare provider. You can also choose to contribute information to support scientific research efforts.

If you choose to contribute to research efforts, all personally-identifying information will be removed, your data will be stored at ATHN, and your blood sample at PSBC in the *My Life, Our Future* research repository.

In the future, scientists and researchers from academic institutions and companies can apply for access to this data to support scientifically-sound research projects. You can opt out and remove your sample from the repository at any time by contacting your HTC.

It is our hope that genotyping will provide you and your family with a better understanding of your hemophilia today, while helping to advance the breakthrough treatments of tomorrow.

Let's make knowledge hereditary.