

Lessons Learned from the Development of an Educational Curriculum for Potential and Confirmed Female Carriers of Hemophilia

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Introduction

Hemophilia is an X-linked, inherited bleeding disorder, characterized by the deficiency or absence of a clotting protein in plasma, leading to prolonged bleeding in affected individuals. Priority has historically been on treatment of affected individuals, with less emphasis on identification and education of female relatives who may be hemophilia carriers. Carriers can sustain complications from injuries and surgery, and they and their offspring are at risk for serious bleeding complications without appropriate care around childbirth. Females with a family history of hemophilia may be unaware of their potential carrier status or may not understand the implications for themselves and their offspring. Carrier identification and education helps to promote optimal health outcomes and allows females and their partners to make informed family planning and healthcare decisions.

Objectives

Overall Goal:

Improve outcomes for carrier females and their offspring

Objectives:

- Develop a curriculum for educating and providing resources to carriers and potential carriers of hemophilia
- Coordinate two pilot programs to evaluate the curriculum and make adjustments to the curriculum, accordingly
- Disseminate the curriculum to assist providers and others to support outreach to and education of this patient population

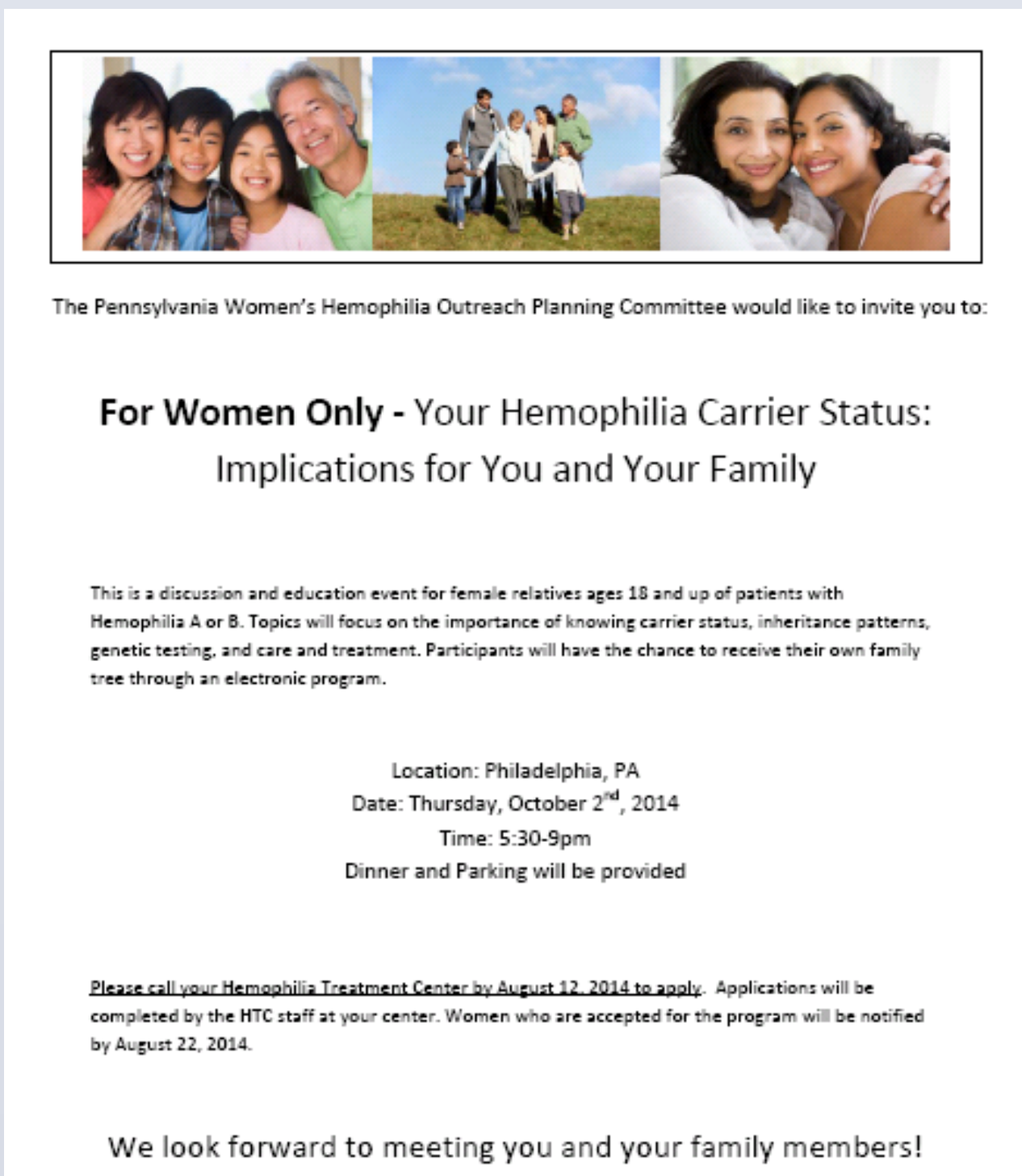


Figure 1. Recruitment flyer
This is the recruitment flyer that was used for the 1st pilot program.

Planning Committee

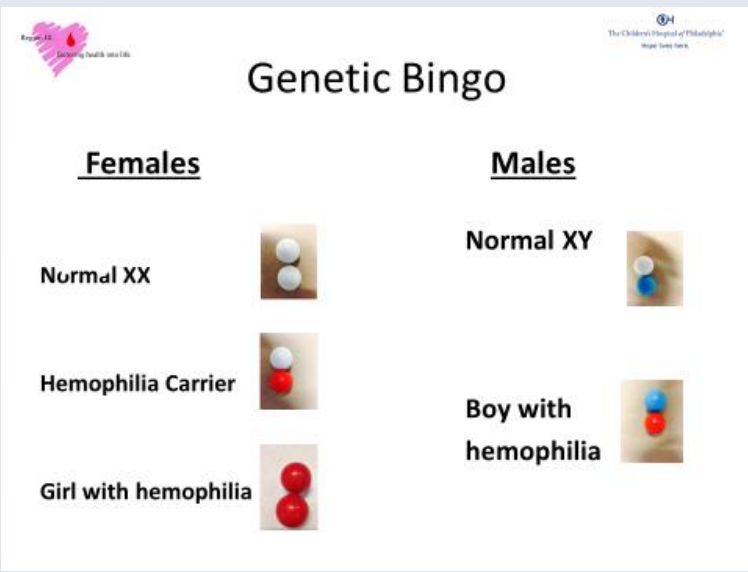
A multidisciplinary planning committee was created for this project. The committee included a social worker and two nurses with extensive experience in the field of hemophilia, a licensed genetic counselor who works full-time at a Hemophilia Treatment Center (HTC), and a project coordinator. The committee decided that a critical component of the curriculum would be the clinical picture of hemophilia today, in order to address any misperceptions based on family members’ past experiences. The committee also decided that the intended audience for the curriculum would be females with a family history of hemophilia age 18 and over.

Methods

Curriculum development: Several conference calls and an in-person meeting were held with the planning committee to develop the curriculum. Final curriculum topics included: overview of hemophilia, implications of carrier status for females and their offspring, inheritance of hemophilia, risk assessment via pedigree analysis, and testing options. Effort was made to integrate engaging aspects into the curriculum, including case studies, personalized pedigrees, and genetic bingo. Materials to support the curriculum were developed, including flyers, forms, agendas, and slides. All materials were created with the intent that they can be used to conduct the program in its entirety, or to supplement education for carriers and potential carriers independent of the program.



Figure 3a. Genetic Bingo Activity
Figure 3a depicts a bingo game that was utilized to demonstrate odds and randomness of pregnancy outcomes for different risk assessment scenarios (i.e. unaffected father, carrier mother). One cage represented “mom” and the other represented “dad”. A red ball, white ball and blue ball were used to represent an affected X chromosome, an unaffected X chromosome, and a Y chromosome, respectively. Volunteers dispensed one ball from each cage, simulating a possible pregnancy outcome. Figure 3b. depicts the various combinations of potential outcomes from the genetic bingo activity.



Pilot programs: Two pilot programs were held: one in Philadelphia, PA in October 2014 followed by one in Pittsburgh, PA in February 2015. Female relatives of individuals with hemophilia known to local HTC were recruited using a variety of methods, including mailing flyers to HTC patients and discussing the program during clinics. A movie ticket incentive was made available for the second pilot program, in an attempt to increase attendance. On a case by case basis, females under age 18 were allowed to attend, if accompanied by a female parent/guardian. Each pilot program lasted 3.5 hours, which included time for a meal, the complete curriculum and discussion. Participants were provided with a binder of materials including slides, a resource list, pre- and post-tests, and a program evaluation. To promote direct application of information, personal pedigrees were distributed to participants who submitted their family history information prior to the event.

Disseminate curriculum: Final revisions were made to the curriculum materials and the pre- and post-tests as a result of feedback and insight from the two pilot programs. A Facilitator Guide was created. USB drives containing the Facilitator Guide and slide sets were created and are available for distribution nationally, as a resource for providers.

Results

A total of 24 individuals participated in the two pilot programs. Participants included known carriers and potential carriers, individuals of child-bearing and non-child-bearing age, and both parous and nulliparous individuals. Participant evaluations were positive, with 23 participants rating the program as “very good”. Of the 19 pre- and post-tests which were evaluable, twelve participants had an improvement in score, three participants had no change in score, and four participants had a decline in score.

	A1	A2	A3	A4	A7	A8	A10	A11	A12	A13	A14
Pre-test Score	5	4	3	10	7	7	7	8	9	9	10
Post-test Score	8	9	8	10	7	9	10	9	6	10	10
	*	*	*	^	^	*	*	*	#	*	^
* Improvement in score (n=7)											
^ No change in score (n=3)											
# Decline in score (n=1)											

Table 1. Comparison of Pre- and Post-test Scores from the 1st pilot program
This table compares the pre- and post-test scores for participants of the first pilot program. Of the eleven individuals who had pre- and post-test scores which were able to be evaluated, seven had an improvement in score, three had no change in score, and one had a decline in score. Of note, two of the individuals with no change in score had a perfect score and the individual who had a decline in score did not complete the entire post-test.

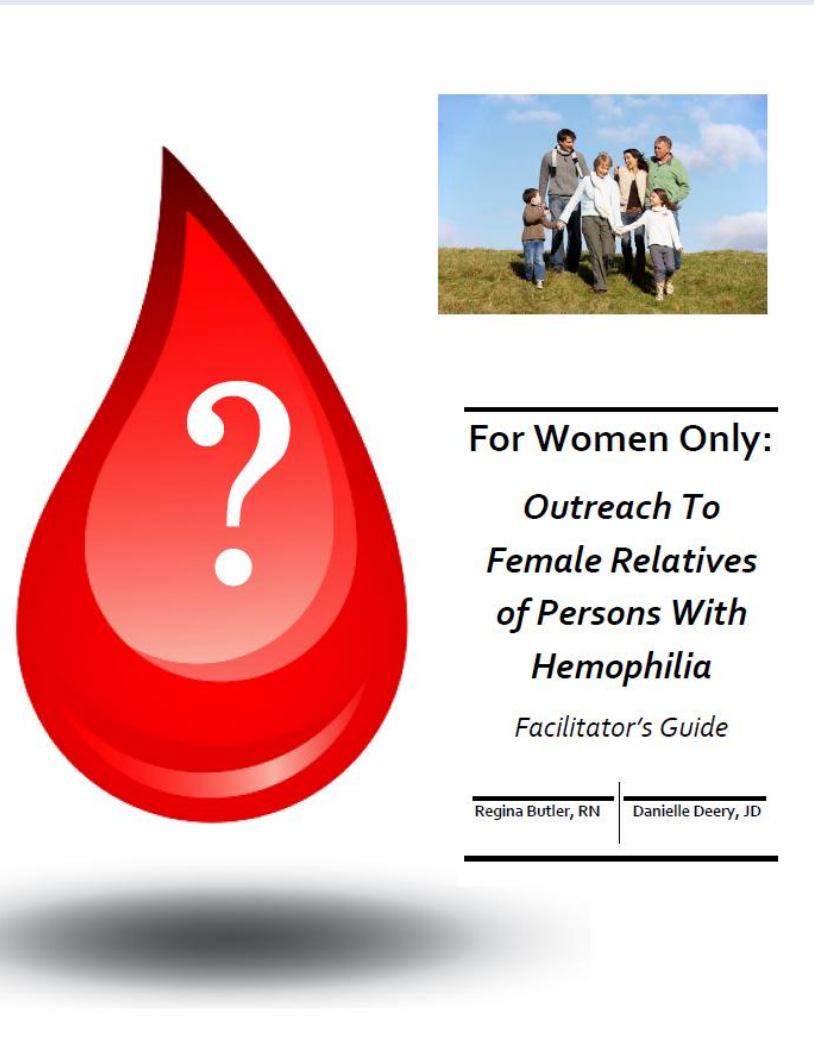


Figure 4. Curriculum Facilitator’s Guide
A Facilitator’s Guide was developed for this program, in order to support providers who wish to utilize the program in whole or in part. It includes information and tips on topics such as role of the facilitator, method of delivery, recruitment materials, preparation for the program, and the program content.

Lessons Learned

- A multidisciplinary team was helpful for creating the curriculum and facilitating the program.
- Recruitment of at-risk family members for a stand alone program can be challenging, but successful.
- Comments and evaluations show that participants were very satisfied with the program’s curriculum.
- Pre- and post-test scoring determined that learning took place overall.
- Strong interest from HTC staff throughout the U.S. has been generated, as evidenced by the number of requests received for the curriculum guide.

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