NHPCC Projects of National Significance
Female Relative Outreach Program

Regina B. Butler, R.N.
Female Relative Outreach Program: 
For Women Only

• Overall Goal:
  – Improve outcomes for carrier women and their children

• Objectives:
  – Identify female relatives at risk
  – Educate about hemophilia, genetics
  – Provide resources and information about genetic testing
  – Avoid complications
    • Risks to health of women
    • Risks to health of baby boys
  – Prepare/ disseminate curriculum to assist Providers and others in outreach/ education
BACKGROUND

• NHPCC Needs Assessment
  – HTC survey – TA for genetic education identified
    • 41% of social workers
    • 40% of hematologists
    • 39% of nurses
  – Patient Survey – Genetic testing
    • 13% report need; 12% report services provided
    • 27% report services do not meet need
    • Numbers small, but need indicated
BACKGROUND

• Mid Atlantic/Region III emphasis on genetics
• Increased availability of genetic testing
• Regional experiences
• Unprepared new parents
• Serious, preventable complications when carrier status is not identified or women do not have needed information
Why is it Important?

- 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
Preventable Complications

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

- 27 year old woman, first pregnancy
- Two older maternal relatives with hemophilia
- Family history not elicited by providers
- Delivered healthy baby girl
- Significant post partum hemorrhage
- Required three RBC transfusions and partial hysterectomy
Preparing for Program

• Develop Flyer
• Develop invitation letter for HTCs to send to families
• Contact all HTCs and other providers in area
• Advertise in Chapter materials

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**
Preparing for Program

- Acceptance letters and reminder calls
- Adapt family history survey
- Distribute to all registered participants
- Returned prior to program for preparation of individual pedigrees for each participant
- Some had multiple female relatives at risk previously unidentified by family or HTC

August 28, 2014
Dear _________________

We are pleased to accept your registration to the Female relative Outreach Program on October 2, 2014 at 5:30 – 9:00 PM
The Hilton Hotel
4200 City Line Ave, Philadelphia, PA 19131
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 Regina Butler at Butler@email.chop.edu or fax it to her at 267--- ---
If you need help completing the survey, please call your HTC for help.............
Curriculum Development

• Avoid traditional medical model “talks”
  – Interactive
  – Employ Case Studies
  – Provide individual family pedigrees
  – Use sample pedigrees to illustrate patterns and who may be at risk

• Facilitator Guide:
  – Step by step instructions with time guidelines
  – Materials
  – Handouts
  – Resources

• Create Program that can be duplicated easily
Curriculum Development

• Pilot program
  – Evaluate
  – Pre and Post Tests
  – Revise
  – Pilot second time

• Prepare package for distribution
Program Agenda

• Introductions
• Group feedback about experiences with hemophilia
• Overview of hemophilia in 2014
  – Progress over previous generations
  – Compare with family experiences of participants
  – Symptomatic carriers
• Why it matters to these women
  – Case studies, Audience feedback
Agenda

- Genetics of Hemophilia
  - Family history
  - Personalized pedigrees

- Testing
  - Difference between genetic testing and factor levels
  - Importance of factor levels in known carriers
  - Recognition of personal family preferences for age of genetic testing

- Resources
  - Participant Binders
    - Copies of all slides
    - Brochures
    - Literature
    - HTC contact information
  - Information
  - Counseling
  - Assistance with details of education and testing
Genetic Bingo
Genetic Bingo

**Females**

- Normal XX
- Hemophilia Carrier
- Girl with hemophilia

**Males**

- Normal XY
- Boy with hemophilia
Pilot

• First Pilot in Philadelphia, October 2, 2014 5:30-9 PM
  – Flyers and letters to area HTCs to invite women and girls over 16
  – 17 registered participants; 14 attended
  – Faculty:
    • Michelle Alabek, Susan Cutter, Kay Miller, Regina Butler
  – Dinner and parking provided

• Second Pilot: Pittsburgh, Saturday, February 28, 2015
  – Collaboration with local NHF Chapter
  – Faculty: Michelle, Regina and two local providers (TBD)
Evaluations

- 91% rated program as very good
- 9% rated as good
- 55% more likely to talk to female relatives about carrier risks
- 18% less likely (?
- Need to re-word question to identify why not
- 55% more likely to have genetic testing
- 36% known status
- 91% will use new knowledge
Comments

• “Thank you. This was a wonderful presentation”.
• “I appreciated all of the information. I am so glad to know that there are better treatments today to help a hemophiliac live a normal life”.
• “I know a lot more know, which was my goal in coming”.
• “Thank you. Excellent”.
• You ladies did a fabulous job educating the audience and made it very enjoyable. Thank you”.

Next Steps

• Revise pre and post test based on first pilot
• Make adjustments to schedule
• Present second pilot with two of original faculty
• Evaluate
• Revise
• Potential third pilot with no original faculty but one on hand as consultant
• Complete final Facilitator Manual with specific instructions, slides, time frames, resources and tips
• Disseminate curriculum
Female Relative Outreach Program

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Questions?