

Hemophilia Council of California
Advocacy & Policy Webinar



Women and Bleeding Disorders: **How To Be Your Own Best Advocate**



*Presented by
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HCC Executive Director*

HCC's 2020
Advocacy &
Policy Webinar
Series

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WHO AM I?

DR. AMBER FEDERIZO, APRN, FNP-BC

WHO DOES THE WORLD BELIEVE YOU ARE

- Female
- Female with a bleeding disorder
- Mom
- Employee
- Sister
- _____

FEAR

- Why

HOW THE MEDICAL WORLD PERCEIVES YOU IS DEPENDENT ON HEALTH LITERACY

- Health Literacy is the ability with which people have the capacity to obtain, process, and understand health information and can integrate that information to make appropriate health decisions.
 - Impacted by:
 - Culture
 - Medical Jargon
 - Context
 - Situational influences

IMPACTED BY CULTURE

- How we communicate
- How we feel and perceive the world around us
- How we seek care and respond to advice

FOR EXAMPLE

- Carrier
 - What does it mean?
 - Is a male affected with a bleeding disorder a symptomatic carrier too?
 - Am I affected?
 - Is the patient at risk?

MANY LEVELS

- Individuals need to incorporate several formats of information at an ever-increasing pace.
- Insurance changes, research changes, staff changes.
- How to access care.

PROBLEMS WITH A LACK OF HEALTH LITERACY AND ADVOCACY

- Higher use of emergency services
- Increased episodes of hospitalizations.
- Lower ability to access preventative services.
- Higher healthcare costs
- Lower quality of life

EMOTIONS

- Anger is inherent in frustrations but only breeds anger in others.
- Shame is inherent but only leads to silence.
- Health literacy should be emotionless but we are human and fraught with insecurities

HIGHEST RISK

- Older adults
- Poor adults
- Limited education
- Minority
- **WOMEN WITH BLEEDING DISORDERS**

YOUR STORY

- How you tell it.
- How often you have told it.
- Who you tell it to.

SO HOW TO EFFECTIVELY TELL YOUR STORY

- Objective
- Consistency
- Accuracy

**ONE CAN ONLY WALK SO FAR
FROM ONE'S TRUE SELF
BEFORE THE BOND EITHER
SNAPS, OR PULLS ONE BACK.**

- ROBIN HOBB -

Questions?

HCC's 2020
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Thank you for joining us!

Reminder: this webinar is part of a series of educational webinars presented by the Hemophilia Council of California.

A recording and slides will be available in a few weeks at

<http://www.hemophiliaca.org/programs/webinars/>

NEED HELP? Contact Lynne Kinst at (916) 572-7771 or
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