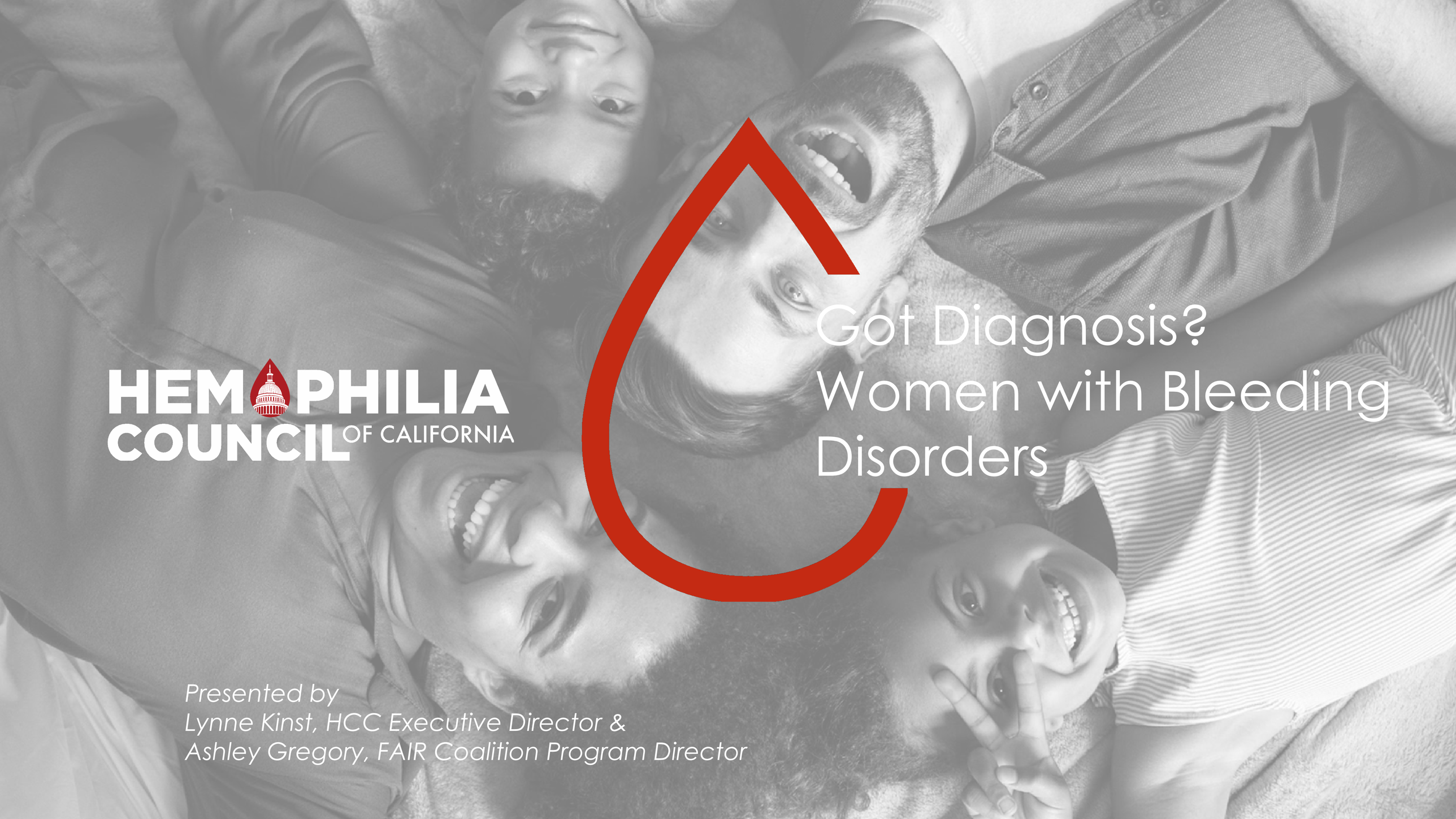

HEMOPHILIA COUNCIL OF CALIFORNIA

Got Diagnosis? Women with Bleeding Disorders

Presented by
Lynne Kinst, HCC Executive Director &
Ashley Gregory, FAIR Coalition Program Director

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Housekeeping in 30 seconds or less

- **Use chat** to ask questions throughout the webinar
- Please **mute** your phone or computer until Q&A (Use *6 to mute or unmute)
- Neither the **Hemophilia Council of California** nor our **speakers** today are providing legal counsel or medical advice.
- This webinar will be recorded and posted **at a later date**
- Find **additional resources & recordings** at www.hemophiliaCA.org/education/webinars

What is the Hemophilia Council of California?

Our **Beginning**

HCC is a 501(c)3 nonprofit organization formed in 1989 to to coordinate the shared advocacy agenda of the four California hemophilia organizations

Our **Focus**

HCC coordinates statewide access, education and advocacy efforts on behalf of individuals living with bleeding disorders and rare or chronic conditions

Our **Advocacy**

HCC advocates to protect access to care, promote progressive treatment options and advance the quality of life for these individuals, families and caregivers

Mission & Vision

Our **Mission**

To improve access to care and treatment options in order to advance the quality of life for people with bleeding disorders through advocacy, education, and outreach in collaboration with our founding member organizations

Our **Vision**

Open access to quality innovative care and choice of treatment for all people with bleeding disorders

What is the problem?

Barriers to Diagnosing Bleeding

- Systemic bias
- Difficulty recognizing and defining excessive bleeding
- Not like the textbook
- Difficulty being referred to right type of hematologist

Who can help you?

- Primary Care Doctor
- OB/Gyn
- Hematologist

When to test

- “Ideally, all (potential) carriers undergo genetic testing to confirm the diagnosis of hemophilia & to establish causative mutation.” – Leebeer
- Any family history is a reason for genetic testing
- Anytime bleeding is impacting daily life and activities it should be investigated

Types of testing to consider

- Genetic testing
- Factor Levels
- PK studies

Access Barriers

Insurance Challenges

- Difficulty getting a referral
- Access to lab testing

Medical Genetics

- "A carrier, as related to genetics, is an individual who "carries" and can pass on to its offspring a genomic variant (allele) associated with a disease (or trait) that is inherited in an autosomal recessive or sex-linked manner, **and who does not show symptoms of that disease** (or features of that trait)." – National Human Genome Research Institute

- "A carrier is a person who can pass an inherited (genetic) disease to their children but does not have the disorder."– MyHealth Alberta

Why does this matter?

- When Medical providers, insurance companies and others outside the bleeding disorder hear the phrase “Carrier” they assume the person does NOT have symptoms
- Essentially, the term “symptomatic carrier” is an oxymoron
- Instead, we need to describe patients as having a family history of bleeding disorders, with related symptoms and request testing and referral to confirm diagnosis
- We need to change our language and be sure that our providers update their language in our medical charts and insurance paperwork also

Other tips

Document everything– logs and photos will go a long way to helping you advocate for yourself and helping your doctor understand what you're facing.

Don't give up!

GHPP & CCS

- Unfortunately, GHPP does not provide coverage for diagnostic appointments or testing. You will have to get a diagnosis in order to apply for GHPP.
- CCS does have some limited coverage for diagnostics, but unfortunately it's unlikely to be very helpful to very many bleeding disorders patients.

Insurance Appeals

- The initial decision from your insurance company is not final – every plan has an appeal process and you should follow it because a high percentage of appeals are overturned.
- Try to get the denial in writing.
- This should include information about how to appeal. Follow the instructions exactly so your appeal isn't tossed on a technicality.
- When calling for assistance, take note of the date, time of your call, name of the person you spoke with and call identification #.
- HCC and others can help.

A personal story – Lew Wyman-Collins

Lew serves on the advisory board of the FAIR Time for women and is a woman with multiple bleeding disorders that had to overcome barriers to diagnosis, care and treatment.

She is currently a NICU nurse at her local children's hospital.

FAIR Coalition, Ashley Gregory

Ashley is a woman with multiple bleeding disorders who advocates for treatment for all through her work with the FAIR Coalition, as well as via her role as the Education and Advocacy Director at the Hemophilia Foundation of Northern California.

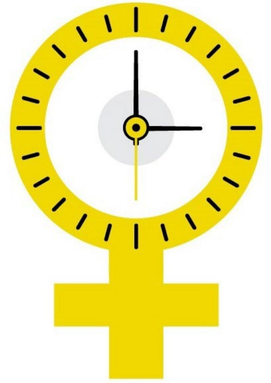
She hopes to have access to treatment for her blood sisters and herself.

FAIR TIME FOR
WOMEN COALITION

(Females Are Important to be Recognized)

If the bleeding goal for men is 0, **why is it not 0 for women?**

Current Problem for XXs



Source: rpth. Volume 6, Issue 1. January 2022. **The lived experience of women with a bleeding disorder: A systematic review.**
Authors: Anna Sanigorska BSc, RN, Steve Chaplin BPharm, MSc, Mike Holland BSc, Kate Khair MSc, PhD, Debra Pollard MSc, RGN.

This systematic review includes research published between 1998 and 2020.

- Women with a bleeding disorder report delayed diagnosis, obstacles to accessing health care, stigma, interference with schooling and work, and poor mental health.
- Diagnostic delay and lack of recognition of symptoms mean treatment and support may not be available.
- Where comparisons with controls were made, women's negative experiences were greater than those of men.
- We do not know enough about the experience of women who live with a bleeding disorder.

These findings have changed little over time.

Coalition Overview

Purpose: This coalition exists to build a grassroots movement to advance equitable access to diagnosis, care and treatment for women and girls and those assigned at birth, with bleeding disorders.

The coalition is governed by an Advisory Board of patient advocates, patient advocacy leaders, physicians and nurses. *Currently this includes Ashley Gregory, Patrick James Lynch, Robert Sidonio, MD, Danielle Nance, MD, Kimberly Haugstad, Steve Long, Janet Brewer, Stormy Johnson, Ray Dattoli, Rocio Nunez, John Martinez, Lew Wyman-Collins.*

FAIR TIME FOR WOMEN COALITION

Coalition Priorities

Drive with urgency to address women's access at HTCs and unaffiliated health centers of:

Diagnosis:

1. Reduce the age of diagnosis
2. Advocate for best practices for diagnosis
3. Improve diagnosis rate
4. Communicate and advance effective terminology

Treatment:

1. Ensure fair and equitable access to treatment options are available across all genders
2. Improve standards of treatment options focused on diagnosis

Care:

1. Ensure equitable care for all with a diagnosis and / or symptoms
2. Increase the number of healthcare providers that treat females
3. Medical school adoption of curriculum that includes women
4. Increase sharing of research addressing females

FAIR TIME FOR WOMEN COALITION

Coalition Objectives

Commitment to Action

1. Challenging and encouraging all stakeholders, including care providers, to **actively engage in championing and improving diagnosis, care, and treatment** for women who bleed

2. Enhancing awareness through **regular communication** with stakeholders and the public about the Coalition's activities and impact

3. Increasing the collective momentum through **communication and storytelling** of a.) women who bleed to document challenges and gaps AND b.) of health care providers who are improving the quality of life for women through diagnosis, treatment, and care

FAIR TIME FOR WOMEN COALITION

2023 Action Plans

1) **Publishing Sign-On Endorsement** to MASAC (#262) and HFA's Bleeders Bill of Rights

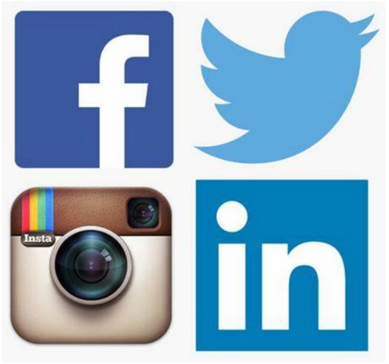
2) **Creating hands-on practical tools and resources** for women to utilize with HCPs

3) **Identify achievable strategies** to support HTCs increasing care to women

4) **Creating a FAIR website and socials** (and)

5) **Keeping community aware of progress**

FAIR TIME FOR WOMEN COALITION



Join the movement!

Need from You!

1. Follow what we're doing on Facebook, Twitter, Instagram and LinkedIn *(website coming soon too!)*
2. Sign up to be on our email list and volunteer
3. Tell others about this work! Help drive excitement and interest in supporting women with bleeding disorders!

Commitment to Action

FAIR TIME FOR WOMEN COALITION

Resources

- Dr. Jill Johnsen, Diagnosis & Treating Females with Bleeding Disorders, HFA Annual Symposium 4/14/2023
- BetterYouKnow.org by National Hemophilia Foundation
- HFA's Project Calls
- NHF's Health Insurance Toolkit
- My Patient Rightswebsite

Overview of Upcoming Webinars

- Fall webinars will focus on understanding and navigating your personal health insurance pathway for the best results.

Thank you to our 2023 Public Policy & Advocacy Webinar Series Sponsors!

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/education/webinars/

NEED HELP?

Contact **Lynne Kinst** at (916) 572-7771 or lkinst@hemophiliaca.org