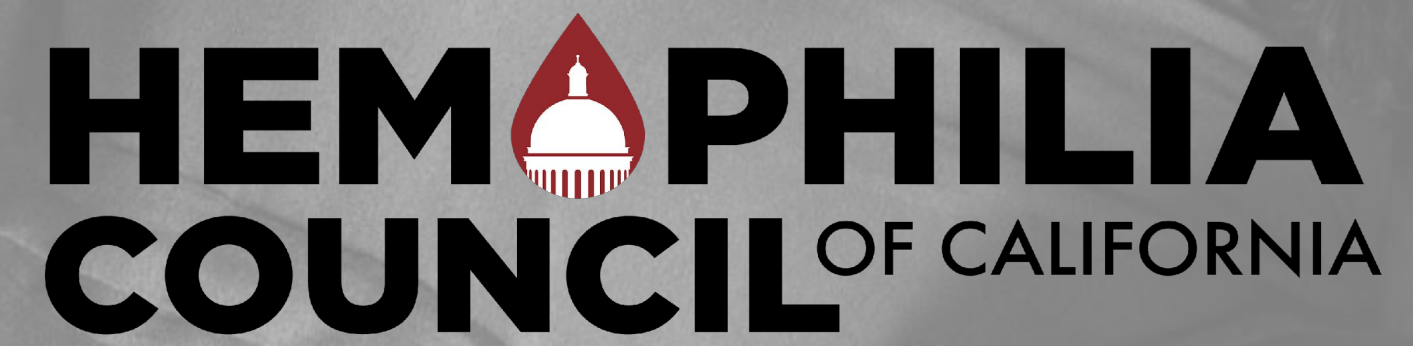




Advocating for Yourself as a Patient

*Presented by
Lynne Kinst, HCC Executive Director &
Dr. Hilda Ding, M.D., M.S., Rady Children's Hospital
Hemophilia and Thrombosis Center*



What is the Hemophilia Council of California?

Our **Beginning**

HCC is a 501(c)3 nonprofit organization formed in 1989 to meet 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

Telling Your Story Matters

- Doctor's office
- Insurance Company
- Emergency Room
- School
- Work
- Advocacy (Legislators and Policy Makers)

Conversation with Dr. Hilda Ding

- . What are the most important things that a patient/caregiver should tell their provider?
- . How should you communicate with your doctor?
- . What should you do to support the telling of your story?



Is there something patients or caregivers do that make it hard for you to hear their story?



What about other
settings?

Consider your purpose

Consider your audience

Consider how much time you have



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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