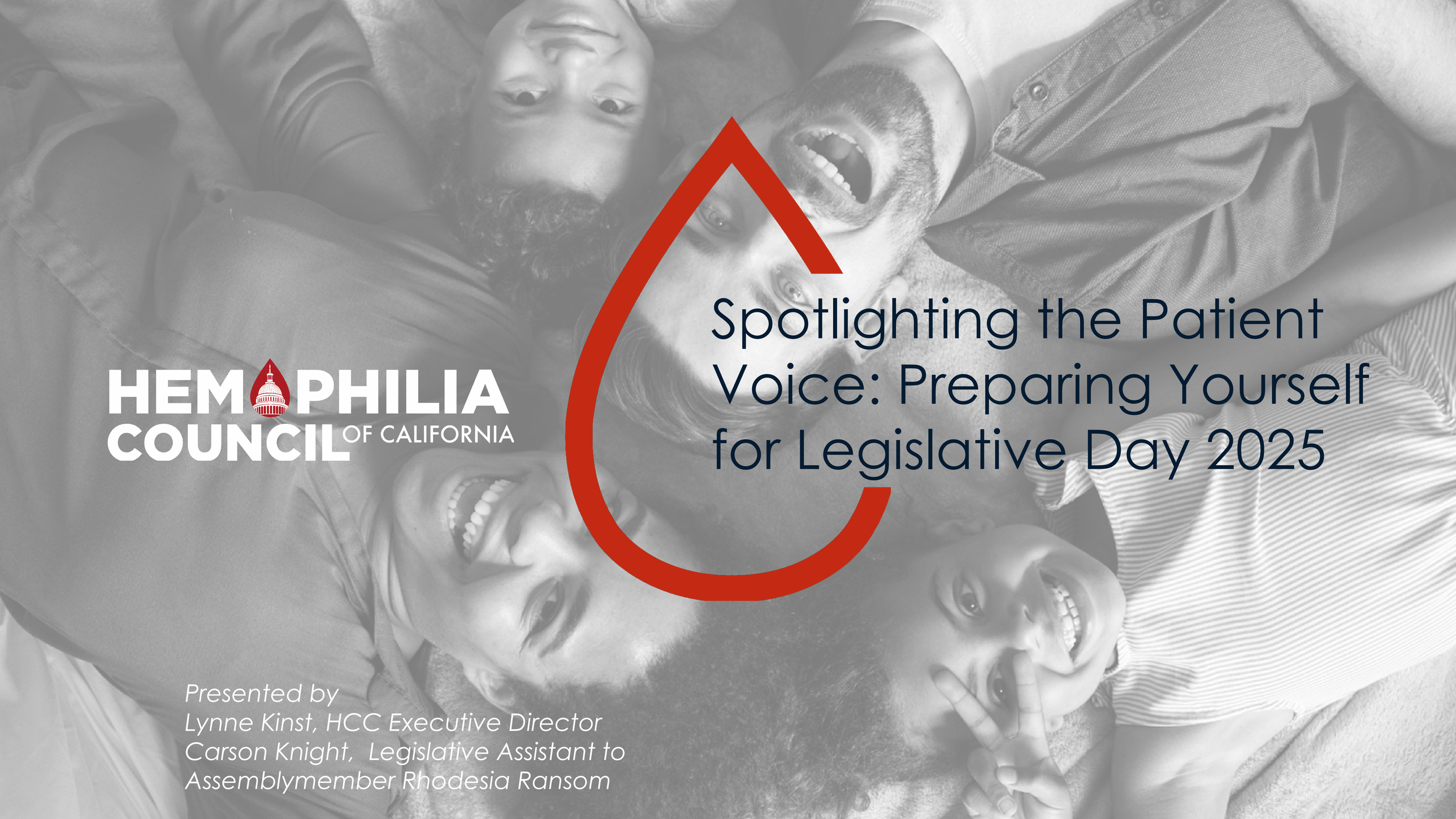

HEMOPHILIA COUNCIL OF CALIFORNIA

Spotlighting the Patient Voice: Preparing Yourself for Legislative Day 2025

Presented by
Lynne Kinst, HCC Executive Director
Carson Knight, Legislative Assistant to Assemblymember Rhodesia Ransom

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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

Legislative Day 2025

What are bleeding disorders?
- Tell your story!

Amplify the Patient Voice – SUPPORT AB 278 (Ransom)

Full funding of CCS, GHPP & Medi-Cal

Bleeding Disorders Substance Use & Mental Health Access Coalition

What is a bleeding disorder?

- Explain in simple terms
- Avoid jargon and acronyms
- Personalize the explanations of bleeding disorders as part of your story
- Address common misunderstandings

Lynne Kinst,
Executive Director, Hemophilia Council of California

Carson Knight,
Staffer, Assemblymember Rhodesia Ransom's Office

What is the Office of Health Care Affordability?

What does AB 278 do?

Office of Health Care Affordability

- Created in 2022, the purpose was to lower health care costs in California by setting spending targets and analyzing market trends.
- Patients with rare and chronic disease often face significantly higher health care costs and require ongoing specialized care. Without direct patient input, cost-cutting measures could inadvertently reduce access to life saving treatments and providers.

AB 278 – Patient Advocate Advisory Committee

- AB 278 establishes a Patient Advocate Advisory Committee within OHCA to ensure patient voices are included in health care policy decisions. The committee would provide recommendations to balance cost control with the need for essential treatments, helping prevent unintended harm to vulnerable populations.

Full Funding for CCS, GHPP & Medi-Cal

- Governor's Budget recommends full funding for CCS (CA Children's Services) and GHPP (Genetically Handicapped Persons Program)
- Legislators and staff will be familiar with Medi-Cal and likely CCS, but may be less familiar with GHPP depending on how much experience they have with health policy and the budget
- Team members can share personal stories about how they have been helped by these programs and how grateful we are for the safety net in California

Preparing For Your Visit

- Review the materials in advance and practice your story
- Business attire is appropriate – bring your red tie or scarf!
- Wear comfortable shoes! Bring a rain jacket or umbrella.
- You will be going through security to enter the Capitol and/or the Legislative Office building (think airport but you won't have to remove your shoes & water is allowed).
- Arrive early – allow time for security and getting lost
- Don't be late – but call the office if you are delayed

Meeting with Your Legislator

- Make sure your entire group has arrived and then check in at the front desk.
- Don't be offended if you're meeting with staff. Never say, "oh, we're **just** meeting with staff." Staff often has more expertise in specific policy areas and is responsible from briefing the Member.
- Start with introductions – constituents should take the lead and go first, but everyone can introduce themselves. It can be good to ask what they know about bleeding disorders.
- Use persuasion and not confrontation – stick to the issues which HCC is focused on today and ensure you're representing yourself, the bleeding disorder community and HCC well.
- Ask permission first, then take a PICTURE!
- Never make up answers if you're unsure how to respond to a question.

Things to keep in mind

- Legislators and staff are people too!
- Don’t be intimidated. Look for ways to connect.
- They want to hear your story!
- Be concise and make your ask clear at the end!

After Your Meetings

- Get a business card of the staff person you met with so you can follow up
- Engage on social media using #HCCLegislativeDay #AB278 #PatientVoice
- Update HCC what you learned in your meeting and any follow up that's needed
- Say thank you! Send an email or a handwritten note!
- Stay informed and follow the process

Participate Virtually

- Send an email to your Assemblymember and Senator
- Engage on social media #HCCLegislativeDay #AB278 #PatientVoice
- Stay informed and follow the process

Social Media Tips & Tricks

- Use a photo to grab attention – a photo from your in-person meeting, a personal photo or the graphic from the toolkit
- Follow your legislators on their active platforms – Twitter, Instagram, Facebook and/or LinkedIn
- Be respectful. Always assume that your posts are public
- Tag HCC and use hashtags #HCCLegislativeDay #AB278 #PatientVoice

  FB - @HemoCouncilofCA
  Twitter - @HemoCouncilofCA
  Instagram - @HemoCouncilofCA

- Check out HCC's Toolkit for more ideas and suggested text

Thank you to our 2025 Public Policy & Advocacy Webinar Series Sponsors!

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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 by the end of this Friday and shared with all participants.

NEED HELP?

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