HEMOPHILIA COUNCIL OF CALIFORNIA

How to Advocate Like a Boss

Presented by
Lynne Kinst, HCC Executive Director

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BAYER

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 2024

What are bleeding disorders?
- Tell your story!

Protect copay assistance – SUPPORT AB 2180 (Weber)

Full funding of CCS, GHPP & Medi-Cal

Patient Assistance Programs and the Threat of Copay Accumulators

COPAY ACCUMULATOR POLICIES

- Used by insurance companies to prevent copay assistance from counting toward a patient's deductible or maximum out-of-pocket expenses
- Allow Payers/Pharmacy Benefit Managers (PBMs) to "double dip" & receive two payments per prescription
  - First with the funds from patients' copay cards
  - Again, with patients' funds once the copay card has been maximized
- Patients' costs increase significantly while insurers and PBMs double their profit

ALL COPAY$ COUNT IN CALIFORNIA

AB 2180:

Ensuring Assistance Goes to Patients, Not Insurers

- Introduced by Assemblymember Dr. Akilah Weber (D-San Diego).
- Will ban the use of copay accumulator policies and require health insurance plans and Pharmacy Benefit Managers (PBMs) to apply any amount paid by the insured through any source to the patient's deductible or out-of-pocket maximum.
- Applies to chronic and terminal disease patients
- Co-sponsored by the Hemophilia Council of California (HCC), the California Rheumatology Alliance (CRA), the Cystic Fibrosis Research Institute (CFRI), Sickle Cell Disease Foundation (SCDF) and the ALS Association.

ALL COPAY$ COUNT IN CALIFORNIA

MYTH VERSUS FACT

MYTH:

Opponents (Insurers and PBMs) argue that Copay Accumulator Programs are necessary because manufacturer copay cards steer people to name brand drugs instead of less expensive generic equivalents.*

FACT:

The vast majority of medications purchased using manufacturer copay cards have NO generic equivalent.

(In 2017, AB 365 in California banned the use of copay assistance coupons to purchase brand-name medications that have generic equivalents covered under the individual's health plan.)

Growing Number of Accumulator Policies
Millions of Californians Affected

- Increasing number of CA regulated plans have Accumulator Adjustment Programs: **Over 50% in 2022**
- Many added in the last few years with **little to no notification** to patients
- Patients are unaware of the practice until they are at the pharmacy counter, where they realize they **must pay full price** (“the Spring surprise”)
- Many patients are forced to **walk away without lifesaving medication**

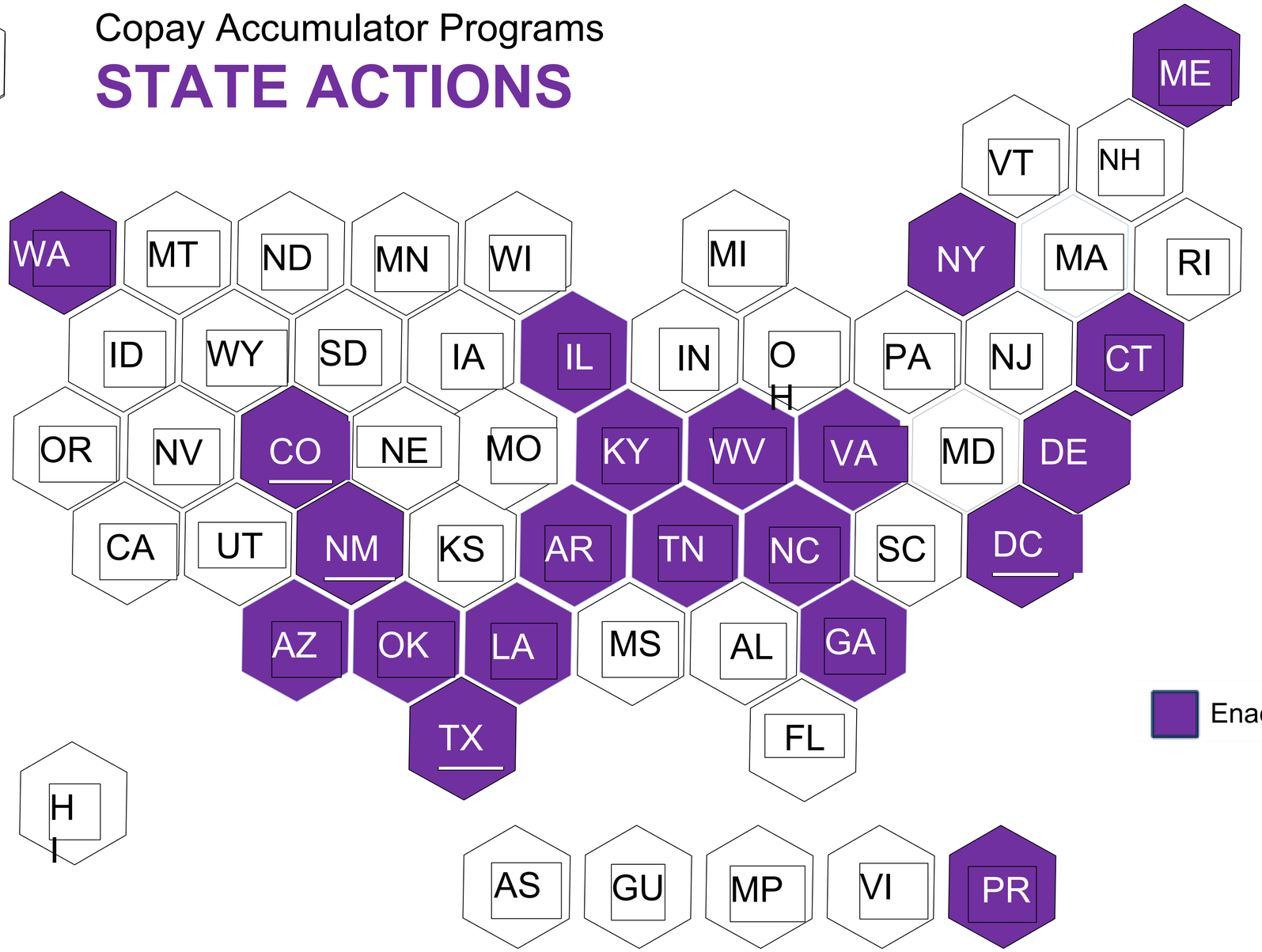
Copay Accumulator Programs Create Health Risks and Exacerbate Health Disparities

- When out-of-pocket costs reach $75 - $125, then more than 40% of patients leave their prescriptions at the counter.
- When out-of-pocket costs reach $250, over 70% of patients leave the pharmacy without their medications.
- Those who cannot afford their pharmacy copays often delay treatment and skip doses, leading to greater risks of health decline and costly emergency room visits.

Medicine Use and Spending in the U.S., A Review of 2018 & Outlook to 2023 (IQVIA, May 2019)

Copay Accumulator Programs

STATE ACTIONS



A total of 19 states, Puerto Rico and the District of Columbia have already passed legislation to ban the use of copay accumulator programs by insurers.

Bipartisan Federal Action: H.R.830/S.1375
Help Ensure Lower Patient Copays Act (HELP Copays Act)

“Requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements. Specifically, plans must apply third-party payments, financial assistance, discounts, product vouchers, and other reductions in out-of-pocket expenses toward the requirements.”

ALL COPAY$ COUNT IN CALIFORNIA

Advocacy & Awareness for Immune Disorders Association (AAIDA), AiArthritis, AIM at Melanoma, Allergy and Asthma Network, Alliance for Patient Access- CA Chapter, Alzheimer's San Diego, American Behcets Disease Association, American Cancer Society Cancer Action Network, CA, Americans for Cures Foundation, Arthritis Foundation, Association for Clinical Oncology, Association of Northern California Oncologists, Autoimmune Association, Axis Advocacy, Breathe Southern California, California Access Coalition, California Association of Physician Assistants (CAPA), California Chronic Care Coalition, California Pharmacists Association, California Rheumatology Alliance, California Urological Association, Carrie's Touch, Central California Hemophilia Foundation, Coalition of State Rheumatology Organizations, Chronic Care Policy Alliance (CCPA), Chronic Disease Coalition, Crohn's & Colitis Foundation, Cystic Fibrosis Research Institute (CFRI), Derma Care Access Network, EB Research Partnership, Emphysema Foundation of America, Everylife Foundation, Global Healthy Living Foundation, Hemophilia Council of California, Hemophilia Federation of America, Hemophilia Foundation of Southern California, HIV+Hepatitis Policy Institute

ALL COPAY$ COUNT IN CALIFORNIA

A **COALITION** of more than 80 community-based organizations, patient advocacy groups and healthcare providers from across the state concerned about the devastating impact the use of copay accumulators has on the most vulnerable patients, including underinsured individuals and patients with chronic conditions who rely on multiple medications to manage their illness.

Immune Deficiency Foundation, International Cancer Advocacy Network, Infusion Access Foundation, International Pain Foundation, Liver Coalition of San Diego, Looms for Lupus, Lung Cancer Foundation of America, LUNGevity Foundation, Lupus and Allied Diseases Association, Inc. , Lupus Foundation of America, Male Lupus Warriors Corp, Medical Oncology Association of Southern California, Inc. , Mental Health America California, California Chapter of the National Association of Social Workers, National Eczema Association, National Hemophilia Foundation, National Infusion Center Association, National Multiple Sclerosis Society, National Psoriasis Foundation, Neuropathy Action Foundation, Osteopathic Physicians & Surgeons of California, Ovarian Cancer Coalition of Greater California, Partnership to Advance Cardiovascular Health, People with Empathy, San Francisco Cancer Women's Network, San Francisco Hep B Free, Spondylitis Association of America, Stanford Copay Coalition, Support Fibromyalgia, Susan G. Komen, The ALS Association, The Defeating Epilepsy Foundation, The Headache and Migraine Policy Forum, The Hemophilia Foundation of Northern California, The Latino Cancer Institute, The Pink Fund, The Wall Las Memorias, Veteran Voices for Fibromyalgia and the We Win Foundation.

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

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

HCC 2024 Advocacy Priorities

Protect Benefits

HCC will advocate to protect benefits and access to Medi-Cal, CCS and GHPP for all patients with bleeding disorders.

HCC will also monitor Medi-Cal Rx and CalAIM to ensure we maximize access and benefits for bleeding disorders patients.

All Copays Count

HCC will work with our coalition partners to introduce legislation to ensure that all copays are applied to a patient's deductible and out-of-pocket expenses to help patients maintain access to medications and health care.

AB 2180 introduced by Weber. Awaiting hearing in Assembly Health Committee.

March BDA Month

As in years past, HCC sponsored a resolution to declare March as Bleeding Disorders Awareness Month and raise awareness about bleeding disorders.

Preparing For Your Visit

- Review the materials in advance and practice your story
- Business attire is appropriate – bring your red tie or scarf!
- But wear comfortable shoes!
- 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.
- 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, and 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 #HCCLegislativeDay #AllCopaysCount
- 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 #AllCopaysCount
- 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 #AllCopaysCount

  FB - @HemophiliaCouncilofCA
  Twitter - @HemoCouncilofCA
  Instagram - @hemocouncilofca

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

Thank you to our 2024 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 by the end of this Friday and shared with all participants.

NEED HELP?

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