Hemophilia Council of California
Advocacy & Policy Webinar

Virtual Legislative Day 2021

A Virtual Advocacy Day Primer

Presented by
Lynne Kinst, HCC Executive Director

and guest speakers
Randi Clites, Advocate
Liz Helms, CCCC Executive Director

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HCC's 2021 Advocacy & Policy Webinar Series

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Housekeeping in 30 seconds or less

- **Use chat** to ask questions throughout the webinar and have them answered at the end
- Please **mute** your phone or computer until Q&A (Use *6 to mute or unmute)
- We strive to provide accurate information, but neither the Hemophilia Council of California or any of our speakers are providing medical advice or legal counsel
- This webinar will be recorded and posted at a later date
- Find **additional resources & recordings** at www.hemophiliaCA.org/programs/webinars

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An Advocacy Story – Randi Clites

Randi is a fierce advocate for patients and families with rare disorders. Her only child Colton, now 18, was born with severe hemophilia and then diagnosed with leukemia at 15 months old. Randi lives in Northeast Ohio with her husband Matt, Colton, and their three dogs.

Randi became an advocate for affordable access to healthcare for medically-fragile children by leading the parent advisory councils at both Akron Children's Hospital and Ohio's Title V Program - Children with Medical Handicaps - through the Department of Health. In 2012, she represented Ohio as a Family Scholar for the Association of Maternal and Child Health Program. Randi helped develop an annual Statehouse Day in 2008 for the hemophilia community that has engaged hundreds of families in State Advocacy. She was the advocacy coordinator for a coalition of providers, patients, and non-profits serving bleeding disorders patients for over 10 years.

She took her passion of working on policy to public office, serving as State Representative for the 75th House District during the 133rd General Assembly. She passed bills to establish a Rare Disease Advisory Council and protect vulnerable patients in Ohio. Randi comes with a lot of non-profit experience in training patients and parents to advocate for access to treatment.

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Legislative Day 2021

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The Hemophilia Council of California (HCC) is the not-for-profit statewide association representing people with rare bleeding disorders such as hemophilia and von Willebrand disease in California. We coordinate advocacy for the four local hemophilia foundations throughout the state and advocate for state budget, regulatory, and legislative policy proposals and programs that maintain and improve care for our patients and families.

Issue #1: Maintain eligibility and benefits for the California Children's Services (CCS) and Genetically Handicapped Persons Program (GHPP) programs:

- These programs provide health care coverage to people with hemophilia and other rare bleeding disorders in CA. This coverage includes factor, ancillary medical supplies, physical therapy and needed medical procedures.
- CCS covers children up to age 21; GHPP covers adults 21 and over.

Issue #2: Ensure continued access to factor, other needed medications and to ancillary medical supplies when the new Medi-Cal Rx Program is established in California (date TBA).

- Patients should continue to receive timely access to their factor, other drugs and related medical supplies when the new Medi-Cal Rx program begins.
- Ensure that the contractor, Magellan Medicaid, authorizes factor in a timely fashion like it is done today and that DHCS staff remains involved from a policy standpoint.

Issue #3: Maintain flexibility for patients during the COVID19 pandemic via TeleHealth when it is not possible to visit their Hemophilia Treatment Center (HTC) *(either via virtual TeleHealth visits or telephonic visits with HTC and other medical caregivers)*

- Flexibility has been put in place by Governor Newsom during the COVID19 pandemic to allow for TeleHealth.
- Support efforts in the State Budget process during 2021 to extend TeleHealth beyond the pandemic.

Issue #4: Support for AB 752 (Nazarian) Patient Choice and Transparency Act

- HCC supports the Patient Choice and Transparency Act which will make prescription drug cost information available at the point-of-care, preventing delays in care and medication nonadherence for the patient while reducing administrative burdens on providers.
- AB 752 enables decision-making to occur where it should – between a patient and their physician. Patients will be central, active stakeholders in their own health and more likely to stick with their treatment plan.

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Liz Helms

Liz Helms has been a leader within the patient's rights movement since her recovery from Temporomandibular Joint Disorder (TMJ) in the mid-1990s. Her vision, breadth of knowledge and unwavering commitment to coalition building, grassroots advocacy, strategic planning, and policy development has earned her immense recognition and respect throughout California and nationally.

After co-founding the TMJ Society of California, a 501(c) 3 non-profit organization dedicated to bringing about changes in health care practices and laws to improve treatment for TMJ sufferers, she has helped shepherd many broad-based, first of-its-kind patient rights laws in California. Liz currently is the President/CEO of the California Chronic Care Coalition, an alliance of non-profit, social consumer and provider organizations united to improve the health of Californians with chronic conditions or diseases.

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AB 752

CALIFORNIA Chronic Care Coalition
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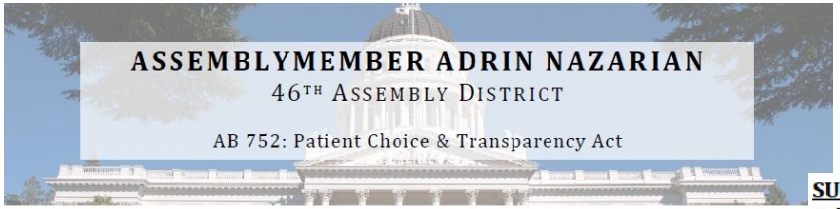

ASSEMBLYMEMBER ADRIN NAZARIAN

46TH ASSEMBLY DISTRICT

AB 752: Patient Choice & Transparency Act

BILL SUMMARY:
This bill would provide patients accurate and patient-specific pharmacy benefit cost and coverage information at the point of care. This bill will empower the patient by providing information about the real-time cost of their specific pharmacy benefit during the prescribing phase thereby improving the patient's ability to begin therapy without delay.

BACKGROUND:
There is currently a lack of accurate, patient-specific cost and coverage information, available electronically, at the time the medicine is being prescribed. For many patients, many caregivers are not obligated to tell their patients what their pharmacy benefits actually offer, often times leaving patients at the pharmacy counter ordering prescriptions they simply can't afford. This often leaves patients in shock and embarrassed at the pharmacy; it leaves others having to duplicate appointments to get the correct medicine with some patients opting not to fill their prescriptions at all. This administrative blunder results in an estimated $289 billion in avoidable health care cost in U.S.

PROBLEM:
Healthcare choices are often decided by what people can afford. Patients, those with and without health coverage, are facing an affordability crisis. Nearly 65% of surveyed patients were financially affected by COVID-19 pandemic, with an estimated 20 million people losing employer-sponsored insurance[1]. With an increase in high deductible plans and cost sharing, patients are becoming more concerned with high out-of-pocket (OOP) costs[2]. Currently, patients rank (OOP) costs and benefit barriers as the most important factors in managing prescription drugs. Studies have shown that patients do not take their medications as directed, if at all, when cost or delay are an issue[3]. This often leads to medication abandonment by patients and is associated with poor clinical outcomes and progression of disease.

Moreover, healthcare providers, pharmacies (also specialty pharmacies) and other allied organizations are challenged by not being able to accurately identify the pharmacy benefit coverage or out-of-pocket at the time of care. These unplanned cost often cause unnecessary administrative costs. Currently 85% of providers list medication barriers like prior authorization (PA) as extremely time-consuming; leaving less time for meaningful interactions with patients[4]. Thus, providers are not able to make fully informed decisions to improve patient access to their medication as it relates to their (OOP) cost. This shouldn't be the case.

SOLUTION:
This bill will allow for empowered conversations and decisions in real-time about what patients have available via their benefit package. Current rules on data sharing inhibit the free flow of information. This bill will authorize that information to flow to all consenting participants

[1] Cover My Meds Patient Survey, 2020
[2] Blavin, F. Karpman, M., & Sommers, B.D. (2018). Medicaid versus marketplace coverage for near-poor adults: effects on out of pocket spending and coverage. Health affairs, 299-307.
[3] Piette, J.D., Heisler, M., & Wagner, T.H. (2004) Cost-related medication underuse among chronically ill adults: the treatments people forgo, how often, and who is at risk. http://doi.org/10.2105/ajph.94.10.1782
[4] Cover My Meds Pharmacist Survey 2020

Updated: 3/30/21

SUPPORT:
California Chronic Care Coalition (Sponsor)
American Diabetes Association
Arthritis Foundation
Axis Advocacy
Breathe Southern California
California Ambulatory Surgery Association
California Chronic Care Coalition- San Diego
California Health Collaborative
California Life Sciences Association
California Pharmacists Association
California Retired Teachers Association
California Rheumatology Alliance
Chronic Care Policy Alliance
Cover My Meds
Emphysema Foundation of America
Hemophilia Council of California
Liver Coalition of San Diego
Looms for Lupus
Multiple Sclerosis Society
National McKesson Corporation
Neuropathy Action Foundation

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CALIFORNIA Chronic Care Coalition
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AB 752

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AB 752

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We are excited to share that CCCC-sponsored AB 752 (Nazarian), the Patient Choice and Transparency Act, will be heard by the Assembly Committee on Health on **Tuesday afternoon, April 13, 2021**. Thank you to all our partners who have supported this legislation with a letter of support so far. Your time and input is valued, and your voice will make a difference for California's patients!

PATIENTS NEED YOUR VOICE - PLEASE CALL-IN AND PROVIDE A "ME TOO" IN SUPPORT OF AB 752:

You can continue supporting California's patients and AB 752 by calling in live to provide a "me too" on behalf of your organization.

Public Access Information "Me Too"

Public Toll Free Number: **(877) 692-8957**

Public Access Code: **2426237**

Thank you for continuing to amplify messages about this important legislation - a like and retweet go a long way! Be sure to follow us @CAChronicCare to watch out for updates online!

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Tips for Telling Your Story

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TELLING YOUR STORY

Here are some tips for constructing your personal bleeding disorders story for talking with a Legislator, Legislative staff or others who you need to influence.

1. Before you start – take a moment to think about what you hope to accomplish by telling your story. Are you seeking to raise awareness? Do you want them to make a decision? Support a bill? This will guide what you include in your story.
2. Remember to be brief. Ask yourself, "Is everything I am about to say necessary to achieve my goal?"
3. Be memorable. Help the person who is listening to your story to SEE your experience by being descriptive and giving an example.
4. Start by introducing yourself – your name, where you live and your connection to bleeding disorders. For example, *My name is Lynne Kinst. I live in Rocklin, California and my dad was born with severe Hemophilia B, which is Factor 9 deficiency. I am also a carrier of the hemophilia gene and have mild Hemophilia B.*
5. Ask if they know anything about bleeding disorders? For example, *have you heard of hemophilia before?*
6. Most likely they won't be very familiar with your bleeding disorder, so take a moment to explain. *For example, people with hemophilia don't make one of the proteins their blood needs in order to clot properly. In order to stop or prevent bleeds, I must infuse expensive medication three times a week. The medication is called clotting factor. If I get a bleed I may have to infuse more often and on average, my factor replacement medication costs $300,000 per year.*
7. Many stories talk about joint pain and swelling in your joints – we all know this is a common problem due to hemophilia or VWD causing bleeding into joints, but your listener may not understand this. If this is part of your story take a moment to explain that joint bleeds are a common problem for people with bleeding disorders and explain the complications and life-long problems this causes without proper treatment. For example, *A common issue for people with bleeding disorders is painful bleeds into their joints. I can remember my dad often getting bleeds in his shoulder, ankle, elbows and knees. When I was in high school he had knee replacement surgery because frequent bleeds caused so much damage to his knee that he didn't have any cartilage left.*
8. Connect your story to one of the issues we are discussing – i.e. the importance of access to health care which has helped you stay healthy.
9. Don't forget – the best person to tell your story is YOU!

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Tips for Virtual Advocacy

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TIPS FOR VIRTUAL ADVOCACY

When you meet with a Member of the California Legislature, expect to be granted about 15 minutes with your Legislator or his or her staff. Don't be offended if you are interrupted. Be flexible and prepared to make every second count.

1. Prepare for your virtual visit – review your materials ahead of time and coordinate or practice with your teammates. Business casual attire is fine. Try to have your background quiet and calm to avoid distractions. If you have pictures or props to share be sure they are nearby.
2. Do not keep the Legislator or staff person waiting. Login a few minutes early to make sure your video and audio are working and you are ready when they arrive in the meeting room.
3. Don't be offended if you are kept waiting. It is sometimes impossible for Legislators or their staff to be prompt. If it is five minutes past the start time, your group leader should contact the staff via email to see if they will still be able to join the meeting.
4. Begin with a quick round of introductions – names, relation to bleeding disorders and your hometown. Constituents of the member should go first and take the lead in the meeting.
5. Do not waste time. Remember why you are there. Following introductions, at least one person should share their story, and then you can go through the issues and "asks" that we are bringing to the Legislator.
6. Use persuasion, not confrontation. Present your concerns clearly and in an orderly fashion. Do not overwhelm the Legislator or staff person with impersonal statistics and details. State the problem in human terms, with real examples of how the situation adversely affects constituents back home.
7. Inform the legislator as to how you will follow-up the meeting. Offer to provide a fact sheet or other supplementary information and further assistance. Do not leave the office without the name of the staff person who will be your contact on the issue.
8. Never make up answers to a question if you are unsure. It is always okay to say you don't know and that you will get back to them with an answer – then be sure to write down the question and ask HCC to follow up.
9. If for some reason the staff cancels or no-shows, use the record feature to record your story and send it to them via email as a follow up.
10. Send a thank you note to the legislator or staff person. If you thank the staff person you met with by name, the letter is sure to end up on the legislator's desk. In your letter, take the opportunity to review the issue. The importance of follow-through cannot be overstated.

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Prepare for the meeting

- Talking Points
- Practice
- Attire
- Background

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Tips for Meeting a Legislator or their staff

- Share the agenda
- Approach with respect, but remember you're important too
- Keep it clear and understandable
- Keep track of time

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What to watch for

- Question cues
- Team Members have something to add
- Support each other

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Next steps

- Tomorrow (Tuesday) – practice with your team.
- Zoom meetings with the Legislature.
- Follow up with a thank you.
- Send an email or use social media to say thank you and reinforce your "ask".
- Phone2Action will be an easy way to complete your follow up. You can also share the P2A link on social media so that others can weigh in with their voice.

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Overview of Upcoming Webinars

Upcoming webinar –

May 12 – How to Access Mental Health Resources

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Questions?

HCC's 2021 Advocacy & Policy Webinar series

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 soon at http://www.hemophiliaca.org/programs/webinars/

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