

Hemophilia Council of California  
Advocacy & Policy Webinar

**Virtually -  
Making Your Voice Heard**



*Moderated by:  
Lynne Kinst,  
HCC Executive Director*

HCC's 2020  
Advocacy &  
Policy  
Webinar  
Series

## Why Virtual Advocacy?



- COVID-19
- Budget Crisis
- Record Unemployment
- Access to Treatment is still critical for every person with a bleeding disorder!
- Virtual advocacy is a great opportunity every year.

Kimberly Chen,  
Principal  
Consultant,  
Senate Health  
Committee



- How to Tell Your Story?
- What do Legislators & staff want to hear?

Alan Moore,  
Legislative  
Aide, Senator  
Holly Mitchell



- How to Tell Your Story?
- What do Legislators & staff want to hear?

June 23, 2020



# Social Media for Virtual Advocacy

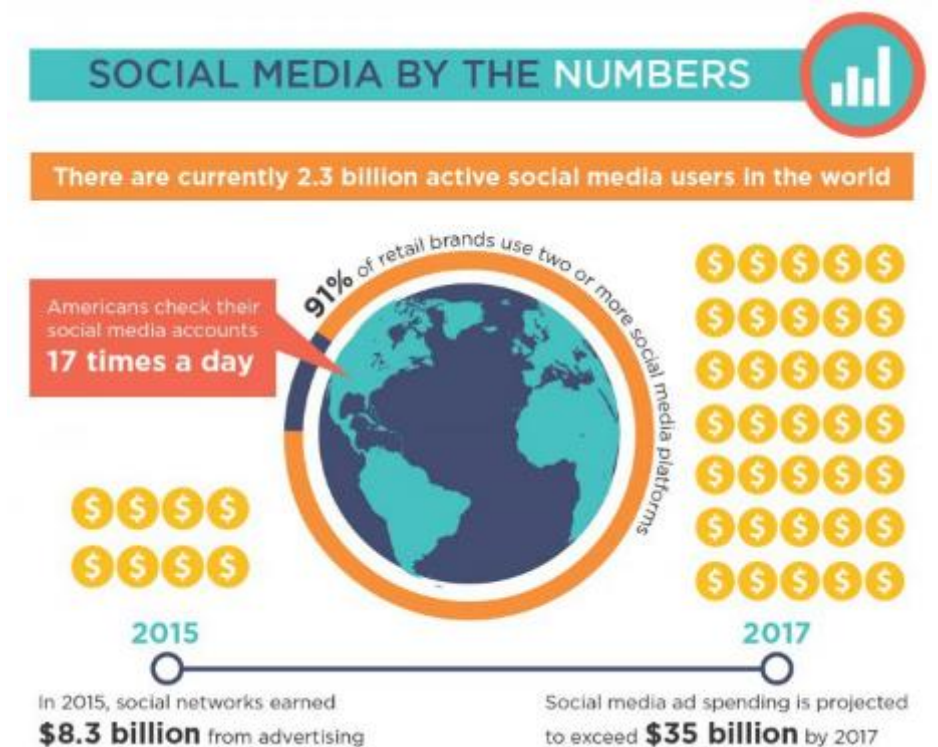
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PREPARED FOR  
Hemophilia Council of  
California

PRESENTED BY  
Kaitlin Perry

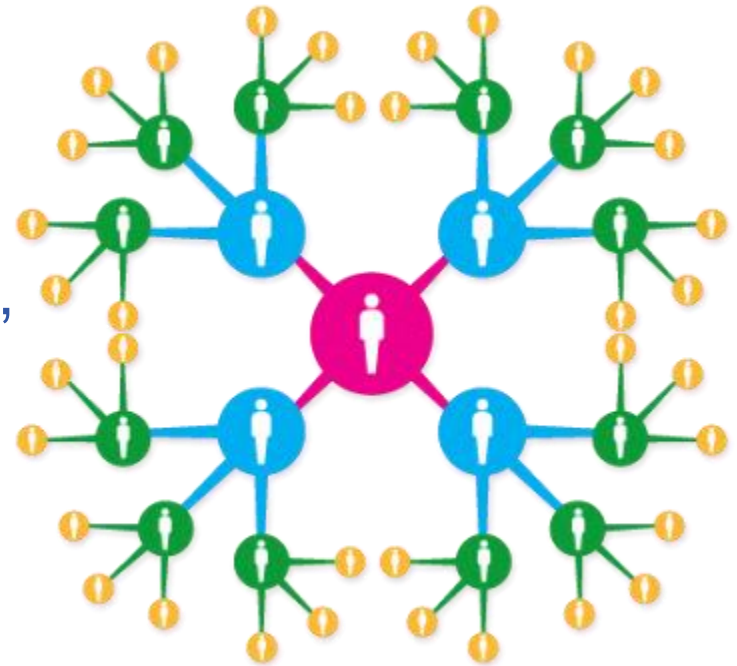
# Why Social Media Matters

- Primary News Source
- Advocacy Launchpad
- Impact Public Policy
- Amplify Voices
- Quick and Easy



# Amplifying Voices

- Connect with other advocates & larger community
  - Raise awareness
  - Coalesce support in an ongoing, meaningful way
  - Help enact specific change for a wide population



# Twitter

- Introduce yourself
- Tag lawmakers (@handle)
- Be succinct with a simple CTA (call to action)
- Sample graphics / photos
- Hashtags (#)
  - #HCCLegislativeDay
  - #Hemophilia
  - #BleedingDisorders





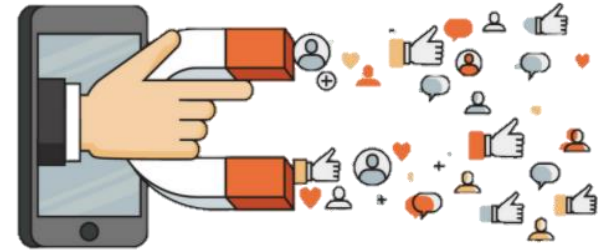
# Facebook

- Dialogue with lawmakers w/out character limit
  - Introduce yourself more fully, include your story & can address the issue in-depth
- Hashtags (#)
  - #HCCLegislativeDay
  - #Hemophilia
  - #BleedingDisorders



# Instagram

- Creative advocacy to cut through the noise
  - Convey stories with emotional impact in a very different way
  - Building your persona online (regular updates to your supporters through “stories” and “posts”)
  - Creating a “brand” around your advocacy or issue
  - Build a base that can translate to other social media channels
  - Engage in real time around key campaign issues
- Hashtags: #HCCLegislativeDay; #Hemophilia; #BleedingDisorders



# Why Your Story Matters

- Ongoing dialogue with your legislator / their staff
  - Your story is unique to you, but can help explain challenges the entire community is experiencing
- Advocate for the larger community in need
  - Legislators and their staff remember stories and faces
  - Helps them understand the human impact of laws they create
- Personal + active + succinct = ***compelling***

# The Issues

- Maintain eligibility & benefits for the California Children's Services (CCS) and Genetically Handicapped Persons Program (GHPP)
- Ensure continued access to factor, other needed medications & to ancillary medical supplies when new CalRX Program is established in January 2021
- Maintain flexibility for patients during COVID-19 via telehealth when in-person is not possible
- Prohibit co-payment accumulator adjustment programs



# Questions?

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## Talking Points for Wednesday

- Maintain eligibility and benefits for the California Children's Services (CCS) and Genetically Handicapped Persons Program (GHPP)
- Ensure continued access to factor, other needed medications and ancillary medical supplies when new CalRx Program is established in January 2021
- Maintain flexibility for patients during COVID19 pandemic via TeleHealth when it is not possible to visit their Hemophilia Treatment Center (HTC)
- Prohibit Co-payment Accumulator Adjuster Programs

## GHPP & CCS



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

## Governor Newsom's Proposals : Cal-Rx

- Cal-Rx proposes to save up to \$178 million by moving Rx purchasing from Medi-Cal Managed Care to Fee-for-Service.
- HCC is monitoring Cal-Rx closely and has received assurances that the State will continue to set the policy regarding Rx approvals and will also review all denials.



## Other proposals & issues to watch



- TeleHealth
- Co-payment accumulator adjusters

## Advocacy Tips & Logistics

- Coordinate with your team before your first meeting.
- Know how to mute and unmute (\*6 on the phone).
- You may have to call-in if you're having internet connectivity issues, but video is ideal.
- Have everyone introduce themselves and a couple of team members briefly share their stories.
- Appoint a team member to touch on each issue item.
- Ask permission to take a photo or screen shot of your virtual visit and post on social media.
- Report back to us how your meeting went.
- Be sure to send a thank you email with the leave behind document.

Register  
now for our  
next  
webinar!

July 16 –

Advocating for Your Child in  
a Changing School  
Environment



## Questions?

HCC's 2020  
Advocacy & Policy  
Webinar series

# Thank you for joining us!

Remember to follow us on social media & use #HCCLegislativeDay

A recording and slides will be available in a few weeks at

<http://www.hemophiliaca.org/programs/webinars/>

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