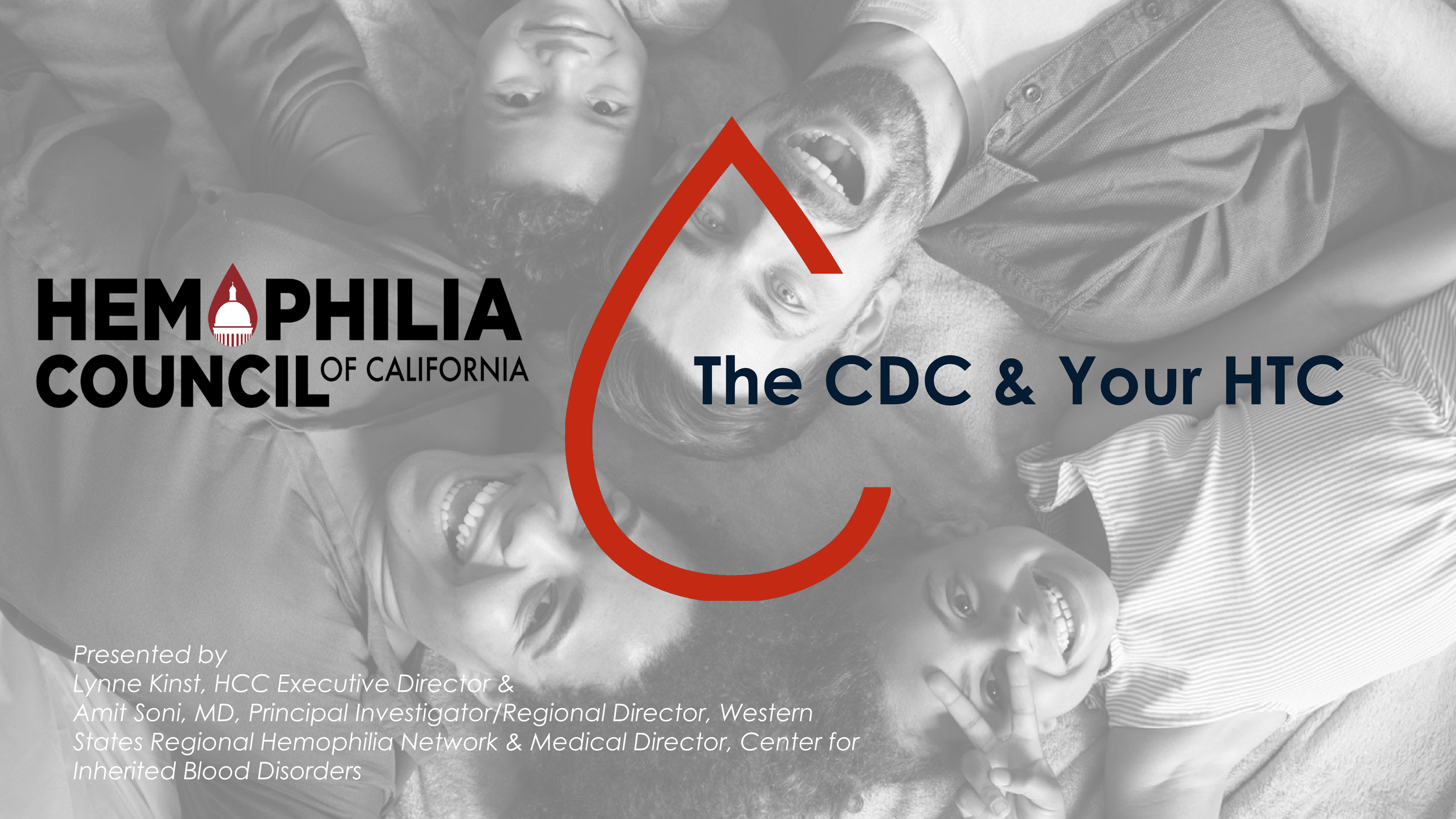

HEMOPHILIA COUNCIL OF CALIFORNIA

The CDC & Your HTC

Presented by
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What is the Hemophilia Council of California?

Our **Beginning**

HCC is a 501(c)3 nonprofit organization formed in 1985 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

What is a Hemophilia Treatment Center?

Hemophilia Treatment Centers (HTCs) specialize in the management of bleeding disorders and are recognized as centers of excellence.

The core team includes: hematologist, nurse coordinator, social worker and physical therapist

Services include: expert care for bleeding disorders, diagnosis, individualized treatment plans, preventative medicine, education and other specialists

What is the US Hemophilia Treatment Center Network?

The Hemophilia Treatment Centers Act of 1975 authorized federal funding to establish a network of comprehensive care centers.

In 1982, the CDC Hemophilia Surveillance Project began, in response to the bad blood crisis.

Also in 1982, the first US cases of AIDS in people with hemophilia via the use of contaminated blood products were reported. Over 60% of US people with hemophilia contracted HIV by 1988.

What is the US Hemophilia Treatment Center Network?

The Veterans Health Care Act of 1992 designated HTCs as original "covered entities" eligible to participate in the 340B program.

In 2003, an assessment from CDC's Hemophilia Surveillance Project demonstrated that no new infections have been linked to blood products used to treat bleeding disorders since 1998.

The Affordable Care Act (ACA), in 2013, officially designated hemophilia treatment centers as essential community providers (among other entities).

Who is served by the US HTC Network?

- Over 60 rare bleeding & clotting disorders treated – including hemophilia, von Willebrand Disease (VWD), platelet disorders & others
- 45,746 individuals were served in 2024
- Eight regions, 149 centers across the US, 10 centers in California

Improved outcomes

- A 40.7% increase in the number of patients over the past 10 years
- 95% of HTC patients were always/usually satisfied with HTC care in a 2023 survey
- Studies have demonstrated a 40% decrease in patient mortality among people with hemophilia treated at Hemophilia Treatment Centers

HTC Funding

- Reimbursement from patients or payors – like Medicare, Medicaid or private insurance. In California, this includes Medi-Cal, California Children's Services (CCS) and the Gentically Handicapped Persons Program (GHPP)
- Health Resources and Services Administration (HRSA) Grant, under Maternal & Child Health Bureau of Special Projects of Regional & National Significant (SPRANS)*
- CDC Community Counts Project, managed by the CDC's Division of Blood Disorders & Public Health Genomics (DBDPHG)*
- 340B program income (authorized by the HRSA grant)*

*at risk

The HRSA Grant

- Each of the eight regions has a regional core center which is the grant recipient and is responsible for administering the grant, including dispersing funds to the HTCs in their region and compiling all the information to fulfill the requirements of the grant.
- Grants are on a five-year cycle. This is year 3 of the grant cycle.
- While the grant amounts are modest, as a HRSA grantee, HTCs are eligible to certify as a 340B covered entity and access lower drug prices through the 340B Drug Pricing Program. This allows the HTCs to generate money through the sale of blood factor replacement products, which they are required to spend on patient care.
- As grantees, all revenue is restricted and must be reinvested in HTC programs to improve patient outcomes. Unlike some other covered entities, there is strong accountability and transparency in the dollars earned and how they are spent.

What is the CDC?

- CDC or the Centers for Disease Control
- The CDC is the national public health organization of the United States, under the Department of Health and Human Services (HHS). The CDC's mission is to protect Americans from health, safety and security threats
- As part of the April 1st reduction in force at HHS, the CDC's Division of Blood Disorders and Public Health Genomics was essentially eliminated. By cutting this division, people with bleeding disorders have lost critical services impacting safety of and access to treatment and care

CDC Division of Blood Disorders

- Community Counts is a public health monitoring program funded by CDC's Division of Blood Disorders & Public Health Genomics. Created in response to the bad blood crisis in the early 1980s, the purpose is to gather and share information about health issues, medical complications and causes of death that affect people with bleeding disorders.
- The American Thrombosis and Hemostasis Network (ATHN) is the recipient of the grant and works with the US Hemophilia Treatment Center Network, who receive funding to support this data collection, to carry out the requirements.
- Unified health data is critical to improve healthcare outcomes and ensure the safety of individuals with bleeding disorders. This data has advanced scientific findings and progress.
- The project also supplies data used to track progress on the objectives of the HRSA grants.

Laboratory Services

- The CDC laboratory – under the Division of Blood Disorders, has also provided critical lab services for our HTCs, including advanced inhibitor testing
- Losing access to this testing will disproportionately impact rural and under - funded regions
- The CDC lab also ensures safety of treatment products for bleeding disorders through surveillance for emerging blood - borne pathogens

Blood Safety

- In addition, HHS disbanded the Advisory Committee on Blood and Tissue Safety and Availability (ACBTSA), the federal advisory committee that provided guidance to the HHS secretary on policy issues related to the safety and availability of blood, blood products, tissues and organs.

Related Federal Issues

Medicaid (in California – MediCal)

- Pending proposals in Congress could cut Medicaid by up to $20 billion dollars annually
- Nationally around 30-40% of bleeding disorders patients receive care under Medicaid. In California, that number is closer to 50%
- In some states, this could result in immediate loss of Medicaid. Others, like California, may try to maintain services but budgets will be immediately impacted
- Cuts to Medicaid have the potential to put access to treatment – including HTCs and blood factor replacement treatments – at risk

ACA – Enhanced Premium Tax Credits

- Set to expire at the end of 2025
- Expanded eligibility to those whose incomes are 400% above the poverty level, who were previously ineligible
- Significantly reduced premiums, with a large percentage of enrollees able to find a plan for less than $10 per month
- The Urban Institute estimates that if the premium tax credits expire, millions will lose coverage or face significant premium increases

What can we do?

- Contact your Congressman & US Senator
- Contact your local State Legislators
- Post on social media
- Submit a letter to the editor
- Stay informed
- Take care of yourselves & one another

What is our ask?

- Reestablish the Division of Blood Disorders at the CDC
- Save Medicaid
- Vote to extend the enhanced tax credits

Thank you to our 2025 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 soon and shared with all participants.

NEED HELP?

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