

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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