



2024 ADVOCACY ISSUES

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: PROTECTING COPAY ASSISTANCE (AB 2180)

Copay assistance is provided by drug manufacturers, charitable foundations and other third parties to help patients pay for their prescriptions, enabling them to afford medications that they would otherwise wouldn't have access to. Copay accumulators are policies through which health plans and pharmacy benefit managers (PBMs) prevent copay assistance given to patients from counting towards their deductible and out-of-pocket maximum.

Many bleeding disorder patients rely on copay assistance to afford their medication but may find that their costs are suddenly much higher than expected, leaving them unable to afford their treatment.

Copay accumulators have a negative impact on patient adherence and health outcomes, leading them to skipping or rationing their medication. Patients living with chronic or complex medical conditions, like bleeding disorders, often require expensive medications that are essential to their health, making copay accumulators particularly burdensome.

An increasing number of state-regulated plans in California have accumulator adjustment policies, with little notification to patients. As a result, patients are often unaware of the practice until they go to the pharmacy counter and realize they must pay the full cost of their medication or walk away without it.

Assemblymember Akilah Weber has been a vocal advocate for patients who are impacted by copay accumulators. This year, she introduced **AB 2180** which will require health plans to count the value of copay assistance toward a patient's deductible and out-of-pocket maximum.

By advocating for fair and transparent practices in healthcare, Assemblymember Weber is working to ensure that patients have access to the care they need to maintain their health and quality of life.



ISSUE #2: MAINTAIN ELIGIBILITY AND BENEFITS FOR MEDI-CAL, THE CALIFORNIA CHILDREN'S SERVICES (CCS) AND GENETICALLY HANDICAPPED PERSONS PROGRAM (GHPP)

The California Children's Services (CCS) is a statewide program that provides specialized medical care and treatment to children with chronic medical conditions or disabilities who are eligible for assistance regardless of their family's income level.

The Genetically Handicapped Persons Program (GHPP) offers comprehensive medical services to individuals with certain genetic diseases or conditions who are at risk of severe physical, developmental, or intellectual disabilities.

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

It is crucial to maintain the eligibility and benefits for CCS and GHPP during a budget deficit year to ensure that vulnerable individuals receive the necessary healthcare services and support.

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