

Talking Points – 2022 Advocacy Issues

Patients introduce themselves and then briefly tell their story to legislators and staff on Virtual Advocacy Day Calls on May 20. Then move on to the key issues:

Issue #1: Maintain eligibility and benefits for Medi-Cal, 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 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.

Issue #2: Expand Medi-Cal to cover undocumented workers ages 26-49:

- Medi-Cal provides access to care for many in our community, and this expansion would increase access to treatment, especially for people in the Latino community with bleeding disorders (about 40% of the patients seen at Hemophilia Treatment Centers speak Spanish as their first language).
- Undocumented workers often cannot find jobs that offer health insurance. Insurance is essential to obtain the very expensive treatments required to adequately manage a bleeding disorder. This Medi-Cal expansion would provide coverage to those workers.

Issue #3: Support Budget Funding for the creation of a Rare Disease Advisory Council (RDAC):

- A Rare Disease Advisory Council would give people with rare diseases, including bleeding disorders, a stronger voice. It would also provide state leaders a conduit to hear from rare disease patients and advocates.
- The RDAC would assist the rare disease community in overcoming barriers to better care and treatment.

Issue #4: Support Budget Funding for our rare disease allies’ in sickle cell (SCD) treatment centers, education and outreach:

- Our allies with sickle cell have long been under-resourced. They need this additional funding to build infrastructure and expand treatment.
- The special care centers that serve SCD patients also serve people with bleeding disorders.
- Strengthening special care centers improves access to care and treatment for both SCD patients and those in the bleeding disorders community.

Contacts:

**Terri Cowger Hill, HCC Legislative Advocate
(916) 952-3431 or terricowger@aol.com**

**Lynne Kinst, HCC Executive Director
(916) 572-7771 or lkinst@hemophiliaca.org**