

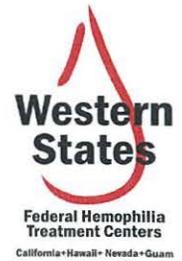


**WESTERN STATES REGIONAL HEMOPHILIA NETWORK
PACIFIC SICKLE CELL REGIONAL COLLABORATIVE**

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*Representing 14 Hemophilia Treatment Centers in California, Guam, Hawaii, and Nevada
Building Sickle Cell Disease Treatment Capacity in Alaska, Arizona, California, Guam, Hawaii, Idaho, Nevada, Oregon and Washington*

July 2, 2015

Jennifer Kent, Director
California Department of Health Care Services (DCHS)
1501 Capitol Mall, 6th Floor
Sacramento, CA 95814

Dear Director Kent: Oppose California Department of Health Care Service (DCHS) Proposal to Transition California Children's Services (CCS) into Managed Medi-Cal Health Plans

The Centers for Inherited Blood Disorders (CIBD) is a not for profit community specialty clinic. We provide team based interdisciplinary diagnostic, treatment, prevention, education, and rehabilitation services to improve health, quality and length of life, and reduce healthcare costs for over 1500 Californians with rare, complex, chronic, catastrophic, and costly blood conditions, such as Hemophilia, Thalassemia, Sickle Cell Disease (SCD), and Metabolic disorders.

Hemophilia, Thalassemia, SCD, and Metabolic disorders are among the most expensive (per capita) and high risk complex rare chronic diseases. Costs, morbidities, and mortality can be avoided by access to the appropriate array of health and behavioral services – which must include rare disorder specialty teams, exemplified by the California Children's Services (CCS) Special Care Centers, and it's CCS Panel Providers. **Therefore, we appreciate this opportunity to express our opposition to the California Department of Health Care Service (DCHS) Model Proposal to Transition Californians eligible for CCS into Managed Medi-Cal Health Plans, as it poses serious risks to medically fragile children.**

We support the guiding principles of the "Whole Child" model. *However, missing from this framework is specific attention to children with rare high-risk, high cost diseases that typically suffer multiple comorbidities. It is unrealistic to expect Medi-Cal Managed Health Plan clinicians to have sufficient knowledge and skill in rare disorder diagnosis, prevention, and treatment. Volume and centralization is essential to provide the quality of care which keeps persons with high-risk high cost rare chronic disorders healthy, and reduces resource utilization.* CCS Special Care Center requirements maintain this expertise.

Hemophilia, Thalassemia, SCD, and Metabolic disorders are high cost, high-risk, catastrophic rare chronic diseases. They differ in causes, symptoms, population prevalence, and treatment. Yet they share these commonalities: advances in pediatric care that improve survival to adulthood, followed by disease progression, impaired quality of life in adulthood often due to lack of access to specialty teams expert in disease management; potentially permanent multi-organ, tissue, and musculoskeletal, and tissue damage; chronic and debilitating pain; lifelong high cost therapies; premature mortality; a dearth of specialists expert in diagnosis and management; high avoidable healthcare services utilization and resulting costs (e.g. emergency room visits, hospitalizations, lost work/school).

Californians with Hemophilia, Thalassemia, SCD, and Metabolic disorders are at high risk for unpredictable and devastating comorbidities. Hemophilia increases risks for progressive musculoskeletal damage - and concomitant chronic pain - from internal bleeding into the joints and soft tissues. This pain can lead to substance use disorders. SCD and Thalassemia increase risk for infections due to the spleen being compromised. SCD also intensifies risks for renal failure; bone disease; stroke and pulmonary hypertension, plus severe unpredictable and chronic pain episodes.

Because of the serious vulnerabilities of CCS population, we are concerned that the Department's CCS proposal:

1. Removes the authority to determine medical necessity for rare disorder care from CCS Special Care Centers and moves it to the Managed Medi-Cal Health Plans. There is no data to support the Department's position that these medically fragile children would be better cared for under the managed care delivery system.

Hemophilia Treatment Centers: Center for Inherited Blood Disorders; Children's Hospital Los Angeles; Rady Children's Hospital San Diego; City of Hope National Medical Center; Guam Department of Public Health and Social Services; Hemophilia Treatment Center Nevada; Orthopaedic Hospital Los Angeles; Stanford University Medical Center; UCSF Benioff Children's Hospital Oakland; UCSF Benioff Children's Hospital San Francisco; University of California, Davis; University of California, San Diego; Valley Children's Hospital;

2. Does not ensure patient access to CCS rare disorder specialty teams, risking beneficiary health, productivity, quality of life and longevity. It increases potentially avoidable hospitalizations, crippling, and the trajectory for negative health and social outcomes, unnecessarily raising costs.
3. Does not ensure a “carve out” of clotting factor, which we support, which is currently Medi-Cal Managed Care the policy under for CCS insured Californians with blood disorders.
4. Does not ensure network adequacy and oversight. The California State Auditor’s June 2015 Medi-Cal Audit found: A) network inadequacy for adults in Medi-Cal Managed Care, B) about 12,500 unanswered calls per month by the Medi-Cal Ombudsman, and C) DCHS did not perform required Medi-Cal managed care plans audits to determine if the beneficiaries’ needs were being met.

We recognize that children with rare chronic, high-risk disorders also suffer from common physical and behavioral health problems. Many adult Medi-Cal beneficiaries with rare disorders have benefitted greatly from access to primary care practitioners and other health care providers to address their more common and/or other health problems that are unrelated to their rare disorder. CCS Special Care Centers coordinate care with these healthcare providers to the extent that beneficiary insurance allows.

However, coordination is a two way street. All too often, narrow insurance networks – including Medi-Cal Managed Health Plans - either outright prohibit or limit beneficiary access to our rare disorder specialty teams, and our full array of diagnostic, prevention, education, treatment, rehabilitative, and pharmacy services. These limitations and prohibitions lead to avoidable costs, morbidity and mortality. **The proposed Whole Child model does not outline mechanisms to avoid these mistakes.**

In sum – we oppose the State’s proposed CCS Redesign, “Whole Child” model as it does not ensure access to CCS Special Care Centers and CCS paneled providers.

We are happy to recommend experts to serve on CCS Redesign work groups. We look forward to continuing to partner with you to improve the health, health care delivery and costs for California’s children with rare high cost, chronic disorders.

Regards,



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