WESTERN STATES REGIONAL HEMOPHILIA NETWORK
PACIFIC SICKLE CELL REGIONAL COLLABORATIVE
The Center for Comprehensive Care & Diagnosis of Inherited Blood Disorders
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Representing 14 HRSA Supported Hemophilia Treatment Centers in California, Guam, Hawaii, and Nevada
Representing 8 HRSA Supported Sickle Cell Centers in Alaska, Arizona, California, Hawaii, Idaho, Nevada, Oregon, Washington

Providing comprehensive diagnostic, treatment, prevention, surveillance, research, and cost effective pharmacy services for a longer, healthier life

February 28, 2017

Nathan Nau, Chief
Managed Care Quality Monitoring
CA Department of Health Care Services
Sacramento, CA

Dear Mr. Nau, RE: Medicaid Managed Care Final Rule: Network Adequacy Policy Proposal

Thank you for soliciting input into the Medicaid Managed Care Final Rule: Network Adequacy Policy Proposal

The Center for Inherited Blood Disorders (CIBD) is a not for profit community specialty clinic that provides 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 complex, chronic, rare and costly blood conditions, such as Hemophilia, Thalassemia, Sickle Cell Disease and Metabolic disorders. These conditions are life-long, debilitating and disabling, with multiple co-morbidities.

While therapies exist, few specialty teams consistently and persistently see sufficient numbers of affected persons to build and maintain expertise in diagnosis and treatment to reduce complications and premature death.

Therefore, to promote the highest quality of care and healthiest life possible for these medically vulnerable Californians, ***we recommend*** *that your proposed Network Adequacy Policy ensure unrestricted access to the blood disorders specialist teams – identified as California Children's Services (CCS) and/or the Genetically Handicapped Persons Program (GHPP). This is regardless of the distance (miles or minutes) between the residence of the Medi-Cal recipient and their SCC, or the county size of residence.* ***We also recommend*** *that this unrestricted access to the SCC be guaranteed not just for the first 12 months of enrollment in Managed Medi-Cal Health Plan, but in perpetuity, with co-management between the Managed Health Plan and the SCC. Twelve months is insufficient for any Health Plan to develop sufficient expertise and in diagnosis/treatment of persons with these rare complex disorders.*

CIBD is a nationally and regionally recognized leader: serving as the prime grantee for federal grants from the Health Resources and Services Administration (HRSA) and the Center for Disease Control and Prevention (CDC). The purposes of these grants are to build rare disorder clinical expertise, conduct bleeding disorder complications surveillance, and sustain regional healthcare delivery systems transformation for over 10,000 persons with Hemophilia, Thalassemia, Sickle Cell Disease, and other rare chronic blood disorders who live in California and the surrounding eight Western US States and Pacific jurisdictions.

Over half quarter of Californians with hemophilia, and over 80% with sickle cell disease are insured by Medi-Cal, CCS and/or GHPP. As most adults with GHPP are mandated to enroll in Managed Medi-Cal Health Plans, and the State plans to move the CCS population in the near future, Medi-Cal policies disproportionately affect access to critically needed integrated, interdisciplinary care teams who are devoted to providing evidence based blood disorders specialty care.

California's 11 HRSA/federally supported Hemophilia Treatment Centers (HTC) concur with the following recommendations. As does UCSF Benioff Children's Hospital Oakland which serves as Co-Principal Investigator on the HRSA Sickle Cell grant. And Sickle Cell Disease Foundation of California.

We have collaborated with your Division for several years. Notably co-sponsoring an innovative statewide seminar for Managed Medi-Cal Health Plan Medical Directors on *Best Practices in Care Coordination* with Hemophilia Treatment Centers in 2014.

For hemophilia, access to the appropriate product and dose of blood factor is critically important to patients and healthcare teams. But factor access is only one aspect of hemophilia care, which alone cannot optimize patient's health outcome, quality of life, and lower cost of long term care for our society or State. *It is critical we craft Medi-Cal Network Adequacy policies that incentivize access to California's network of Hemophilia SCCs and their PHS initiated 340B outpatient pharmacy programs.*[1] This will halt the inefficiencies, waste, and unnecessary costs, while simultaneously linking patients with innovations to improve their health outcome.

Aligning Managed Medi-Cal Network Adequacy policy with access to *SCCs* supports evidence based care, advancing Medi-Cal's commitment to quality. A new clinical guideline accepted by the National Guideline Clearinghouse recommends access to the HTC integrated care model for optimal hemophilia management,[2] mirroring recommendations of the National Hemophilia Foundation[3] and World Federation of Hemophilia.[4] *Hemophilia HTC/SCC* services reduce mortality,[5] morbidity, utilization and costs.[6]

For Sickle Cell many patients are immune compromised, are not given adequate immunizations per NHLBI guidelines, and are not offered hydroxurea – an effective treatment.[7] Few clinicians recognize that Hispanics are at risk for Sickle Cell, leading to preventable morbidity and mortality. Many with Sickle Cell suffer needlessly from silent strokes; others from iron overload due to multiple unnecessary blood transfusions, causing avoidable organ failure. Access to Sickle Cell SCCs is vital to reducing morbidity, mortality and costs.[8]

Policies that strengthen access to SCCs catalyze value and lower costs throughout the lifespan. **SCCs offer 24/7 access to the hematologist devoted to rare blood disorders**. Automatic dialog to expert physicians reduces poor outcomes related to medical errors and increased costs relating to mismanagement. Prevention of frequent problems is a key mission of the SCC teams who advise school personnel about appropriate therapies – reducing avoidable school absenteeism and parental work loss due. Integration of the SCC teams' complex chronic disease care model adds value to Medi-Cal beneficiaries, reducing burden of illness and costs, and numbers deemed permanently disabled[9]

Implications for all Californians: Medi-Cal's network adequacy policy has broad implications to ensure the health of all Californians with hemophilia, bleeding and clotting disorders, not just persons insured by Medi-Cal. *SCCs offer the same array of clinical and care coordination services to all persons**, regardless of their insurance type**.* Hence, SCCs benefit our entire state, helping Californians with blood disorders to stay in school, to work, contribute talents and taxes to the State economy.

Summary: Hemophilia and Sickle Cell Disease are rare, complex, devastating, potentially fatal, and extraordinarily costly disorders. SCC care reduces morbidity, mortality, and healthcare utilization, while managing costs. Using a value framework – based on unrestricted access to SCCs and care coordination with SCCs results in the most sustainable system that promotes the best healthcare outcomes, drives down cost to all payers, and creates excellence in care based on nationally accepted guidelines. With the hemophilia factor induced HIV- epidemic behind us, and new effective Hepatitis C drugs, and with immunizations and hydroxyurea for Sickle Cell disease, our patient populations are living into adulthood. But due to shortages of hematologists devoted to these blood disorders, centers of excellence are only found in the SCCs. Making patient access to SCCs critical to a long healthy productive adulthood to realize the significant investment of SCC care up to age 21.

SCCs can help Managed Medi-Cal achieve the triple aim: the highest quality of care that optimizes patient functioning, reducing waste and cost.

We look forward to collaboration in this important policy endeavor. We value the longstanding support from our state partners in bringing the best care to our California patients and families with inherited blood disorders.

Respectfully submitted,

[redacted]

Regional Director
Director – Center for Inherited Blood Disorders

[redacted]

Public Health Director
Center for Inherited Blood Disorders

On behalf of UCSF Benioff Children's Hospital Oakland – Elliott Vichinsky, MD and Marsha Treadwell, PhD, Co-Principal Investigators for our HRSA Pacific Sickle Cell Regional Collaborative

On behalf of Mary Brown, President and CEO, Sickle Cell Disease Foundation of California

On behalf of California's federally recognized Hemophilia Treatment Centers:
Children's Hospital Central California – Vinod Balasa, MD
Children's Hospital Los Angeles - Guy Young, MD
Children's Hospital San Diego – Courtney Thornburg, MD, MPH
Packard Children's Hospital Stanford – Bertil Glader, MD, PhD
UCSF Benioff Children's Hospital Oakland – Allison Matsunaga, MD
City of Hope Medical Center – Nadia Ewing, MD
Orthopaedic Institute for Children – Doris Quon, MD, PhD
University of California, Davis – Jonathan Ducore, MD, MPH
University of California, San Francisco – Andrew Leavitt, MD and James Huang, MD
University of California, San Diego – Annette von Drygalski, MD

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[1] *Addressing the needs of members with hemophilia in Medicaid Managed Care: Issues and implications for health plans,* Medicaid Health Plan of America Center for Best Practices, July 2013. http://www.hca.wa.gov/assets/program/bdc_MHPA_hemophilia_issue_brief_082113.pdf

[2] Pai, M., et al. "NHF-McMaster Guideline on Care Models for Haemophilia Management." *Haemophilia* 22.S3 (2016): 6-16.

[3] National Hemophilia Foundation, Medical and Scientific Advisory Council Recommendation 132: Standards and Criteria for the Care of persons with Congenital Bleeding Disorders, 2002

[4] Srivastava, Alok, et al. "Guidelines for the management of hemophilia." *Haemophilia* 19.1 (2013): e1-e47.

[5] Soucie, J. Michael, et al. "Mortality among males with hemophilia: relations with source of medical care." *Blood* 96.2 (2000): 437-442.

[6] Soucie, J. Michael, et al. "Home-based factor infusion therapy and hospitalization for bleeding complications among males with haemophilia." *Haemophilia* 7.2 (2001): 198-206.

[7] Yawn, Barbara P., et al. "Management of sickle cell disease: summary of the 2014 evidence-based report by expert panel members." *JAMA* 312.10 (2014): 1033-1048.

[8] Paulukonis S, Raider F, Hulihan M. "Longitudinal Data Collection for Sickle Cell Disease in California: History, Goals and Challenges." A report from the California Rare Disease Surveillance Program, CDC Foundation and California Environmental Health Tracking Program, 2015.

[9] Zhou, Zheng-Yi, et al. "Burden of illness: direct and indirect costs among persons with hemophilia A in the United States." *Journal of medical economics* 18.6 (2015): 457-465.