



March 8, 2024

Secretary Mark Ghaly, MD, MPH
California Health and Human Services
Chair, Health Care Affordability Board
1215 O St. Sacramento, CA 95814

Re: Proposed Statewide Health Care Spending Target - CONCERNS

Dear Secretary Ghaly,

On behalf of the Hemophilia Council of California (HCC) and the California Rare Disease Access Coalition, and the thousands of patients we represent throughout the state, I am writing to express our concern regarding the proposed plan by the California Office of Health Care Affordability (OHCA) to set a 3% spending target, which threatens to have significant adverse effects on rare and chronic disease patients. The potential consequences of OHCA's proposed 3% spending growth target appears to prioritize cost containment over patient access to high-quality care.

Although OHCA was established with the intention of curbing healthcare cost growth while ensuring continued access to high quality treatments and services, it is evident that the proposed spending target fails to strike a healthy balance between the two. Considering OHCA has not been receptive to feedback from the patient community, we are significantly concerned that new cost-reduction strategies will discriminate against the sickest of us.

By prioritizing cost containment over patient needs, OHCA risks setting a dangerous precedent that could further marginalize individuals with rare diseases. We are concerned that a focus on a 3% cost containment will harm people living with rare diseases. Rare conditions cost 3 to 5 times more per person per year than common health conditions. Lack of available treatments is linked to a 21.2 percent increase in total costs per person per year and 373 of the 7,000 known rare diseases cost about \$2.2 trillion per year.ⁱ

While we applaud OCHA for focusing on making health care more affordable, we are concerned that the focus on a 3% cost containment target will harm rare disease patients who often experience a long diagnostic odyssey. It is estimated that rare disease patients face an average of four to five years to receive an accurate diagnosis.ⁱⁱ

We urge OHCA to reconsider its approach and prioritize the needs of rare disease patients in the target-setting process. It is imperative that any spending target be developed in close coordination with patients to ensure it is based on data and analysis and considers the underlying drivers of healthcare costs. By doing so, OHCA can ensure that California's healthcare system remains accessible, high-quality, and equitable for all residents.

Thank you for considering our concerns. I look forward to discussing with your office further.

Sincerely,

Lynne Kinst
Executive Director
Hemophilia Council of California

CC: David M. Carlisle, MD, PhD, Health Care Affordability Board Member
Sandra Hernández, MD, Health Care Affordability Board Member
Richard Kronick, PhD, Health Care Affordability Board Member
Ian Lewis, Health Care Affordability Board Member
Elizabeth Mitchell, Health Care Affordability Board Member
Donald B. Moulds, PhD, Health Care Affordability Board Member
Richard Pan, MD, MPH, FAAP, Health Care Affordability Board Member
Health Care Affordability Advisory Committee Members

ⁱ See Andreu P, Karam J, Child C, Chiesi G, Cioffi G. The Burden of Rare Diseases: An Economic Evaluation. Chiesi Global Rare Diseases. Available at https://chiesirarediseases.com/assets/pdf/chiesiglobalrarediseases.whitepaper-feb.-2022_production-proof.pdf. Accessed 6/10/2022. See also Tisdale A, Cutillo CM, Nathan R, et al. The IDeaS initiative: pilot study to assess the impact of rare diseases on patients and healthcare systems. *Orphanet J Rare Dis.* 2021;16(1):429. doi:10.1186/s13023-021-02061-3.

ⁱⁱ See Marwaha S, Knowles JW, Ashley EA. A guide for the diagnosis of rare and undiagnosed disease: beyond the exome. *Genome Med.* 2022 Feb 28;14(1):23. doi: 10.1186/s13073-022-01026-w. PMID: 35220969; PMCID: PMC8883622.