



May 21, 2018

The Honorable Connie Leyva
California State Senate
State Capitol, Room 4061
Sacramento, CA 95814

Dear Senator Leyva:

The undersigned organizations collectively represent and assist thousands of Californians with a variety of rare, chronic, and life-threatening illnesses. We write to express our concern about Senate Bill 1156, which could limit vital patient assistance and place undue burdens on patients already struggling with debilitating conditions.

Californians living with chronic and life-threatening illnesses, such as cancer, autoimmune, and rare genetic diseases, often face prohibitive costs to simply maintain their health insurance. To bridge this gap, non-profit premium and cost-sharing assistance charities temporarily step in to help patients cover the costs of the care they need to effectively manage their conditions and live healthy, productive lives. This safety net has supported the patients who fall through the cracks of our system for almost three decades and they do so at no added cost to the public.

While we appreciate your goal of promoting affordability for skyrocketing premiums and ensuring compliance with federal guidelines of patient assistance, without amendments SB 1156 has the potential to effectively eliminate premium charitable assistance in California. As drafted, the bill relies on regulators to define whether an entity "receives the majority of its funding from one or more financially interested health care providers" and does not define the term "health care providers," which leaves too much ambiguity and the possibility for insurers to interpret the term as broadly as possible.

Additionally, patient assistance organizations, in compliance with federal oversight guidelines, provide financial aid based on both diagnosis and financial criteria. If these organizations are subject to this bill, by mandating that consideration for assistance eligibility be solely based on income, SB 1156 would allow health insurers to wholesale deny patient assistance across the board. Not only would this harm patients, it would also set a dangerous precedent for other states to follow.

SB 1156 also requires recipients of assistance from entities subject to its provisions to annually apply for Medi-Cal and receive a denial. This is an unnecessary burden for patients. If a patient receiving premium assistance is not on Medi-Cal it is either because (1) they do not qualify for the program or (2) they choose not to be on Medi-Cal and instead on a private plan. We support patient choice and feel as though insurers and the state of California should not force patients onto certain programs when they have other choices. Aside from limiting patient choice, the added task of annually applying for Medi-Cal is an added stress that patients living with rare and chronic diseases do not need.

If SB 1156 were to pass, the results could be potentially catastrophic to thousands of patients who currently depend on premium assistance. They would no longer be able to afford their private plan and would need to go through the arduous process of finding coverage. Many of them will spend down to qualify for Medi-Cal, ballooning the state budget and removing the patient's choice for coverage. Some will try to become voluntarily disabled, embarking on a 29-month approval process in which they'll need coverage while waiting for approval. Sadly, some will rely on the emergency room for their care, negatively impacting their treatment adherence and health outcomes.

The focus of our charitable organizations is on the well-being of the patients we are dedicated to serving. Unfortunately, the focus of those groups supporting this legislation is solely on profit, as they have a financial incentive to remove sicker and more costly patients from their plans. We believe that a patient receiving premium assistance should be able to afford a plan that best fits their medical needs and should not be forcibly steered from that plan by insurers looking to save money. These discriminatory practices would effectively create a new pre-existing condition for high-cost patients who receive assistance, which violates the letter and spirit of the Affordable Care Act and other patient protections we fought hard to attain.

On behalf of the thousands of patients we represent, we voice our concern about SB 1156 and, unless amended, express our opposition. We urge you to significantly change the legislation to better serve patients and we look forward to working with you to do so.

Sincerely,



Bill Remak
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California Hepatitis C Task Force
Coachella Kidney Institute
Chronic Disease Coalition
Fabry Support & Information Group
FAIR Foundation
Good Days
Kidney Institute of the Desert
La Quinta Kidney Center
Neuropathy Action Foundation
Patient Services Incorporated
Pulmonary Hypertension Association
Rancho Mirage Kidney Institute
US Hereditary Angioedema Association

CC: Senate Appropriations Committee members