

August 15, 2018

Assembly Appropriations Committee
California State Assembly
State Capitol, Room 2114
Sacramento, CA 95814

Oppose Unless Amended – S.B. 1156

On behalf of patients we represent, we are writing today to express our deep concerns about Senate Bill 1156. While we understand the intent of the legislation and share concerns about ensuring that premium assistance is making health insurance more affordable to those in need, S.B. 1156 could limit vital patient assistance and place undue burdens on patients already struggling with demanding conditions.

Californians living with chronic and life-threatening illnesses often face prohibitive costs to simply maintain their health insurance. To bridge this gap, patient assistance programs (PAPs) temporarily step in to help patients cover the costs of the care they need to effectively manage their conditions and live healthy, productive lives. Through premium and cost-sharing assistance, these independent, bona-fide charities have formed a safety net that has supported the patients who fall through the cracks of our system for almost three decades, doing so at no added cost to the public.

We all agree that skyrocketing health care costs are financially crushing patients. Unfortunately, S.B. 1156 as written would exacerbate this issue by potentially making premium assistance that thousands of Californians depend on harder to obtain. Patients who previously depended on assistance 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.

While we oppose S.B. 1156 in its current form, we believe that these modest modifications to the language will preserve both the legislation's mission to address specific concerns about patient assistance and the mission of bona-fide charitable assistance to help rare and chronic disease patients in need. Our recommendations are as follows:

- 1) As drafted, the bill seeks to cover PAPs that receive the majority of their funding from "financially interested health care providers." The term "health care providers," is currently defined as "any professional person, organization, health facility, or other person or institution that delivers or furnishes health care services." This definition leaves too much ambiguity and the possibility for insurers to interpret the term as broadly as possible. We urge the committee to amend the language to the following, which is based on an existing definition for health care provider in California Code:

“Health care provider” is defined consistent with the California Code, Code of Civil Procedure § 425.13 and means any person licensed or certified pursuant to Division 2 (commencing with Section 500) of the Business and Professions Code, or licensed pursuant to the Osteopathic Initiative Act, or the Chiropractic Initiative Act, or licensed pursuant to Chapter 2.5 (commencing with Section 1440) of Division 2 of the Health and Safety Code; and any clinic, health dispensary, or health facility, licensed pursuant to Division 2 (commencing with Section 1200) of the Health and Safety Code. “Health care provider” includes the legal representatives of a health care provider.

Health care provider must be defined in the clearest of terms as to not leave ambiguity for all parties involved, and especially the regulators enforcing its provisions. Doing so will clarify whether all PAPs operating as bona-fide charities are subject to the legislation’s provisions.

- 2) To provide assistance, PAPs must be awarded a positive advisory opinion from the Office of Inspector General at the Department of Health and Human Services. In accordance with these opinions, assistance programs’ eligibility for patients have been based on a first-come first-serve basis centered on diagnosis and financial need. This practice has been the status quo for assistance programs for three decades and follows suit with other disease-specific government assistance programs, such as the Ryan White AIDS Drug Assistance Program (ADAP). Currently there is language in S.B. 1156 which would mandate that PAPs base assistance eligibility solely on an applicant’s income.

If PAPs are intended to comply with this legislation, **we respectfully request amending this section to include diagnosis-based programs or removing that income be the sole consideration**. The language as it stands could have the potential to eliminate thousands of Californians’ ability to access premium assistance programs and would also set a dangerous precedent for other states to follow. Income and financial need should be a key consideration for assistance, but diagnosis should also be included when making such an assessment.

The focus of our 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 S.B. 1156 and, unless amended, express our opposition. We urge you to change the legislation to better serve patients and we look forward to working with you to do so.

Sincerely,

American Liver Foundation
California Hepatitis C Task Force
California Chronic Care Coalition
California NAACP
Chronic Disease Coalition
Fabry Support & Information Group
FAIR Foundation
Good Days
Neuropathy Action Foundation
Patient Services Incorporated
Pulmonary Hypertension Association
US Hereditary Angioedema Association

CC:

Assembly Member Lorena S. Gonzalez Fletcher (Chair)
Assembly Member Frank Bigelow (Vice Chair)
Assembly Member Richard Bloom
Assembly Member Rob Bonta
Assembly Member William P. Brough
Assembly Member Ian C. Calderon
Assembly Member Ed Chau
Assembly Member Susan Talamantes Eggman
Assembly Member Vince Fong
Assembly Member Laura Friedman
Assembly Member James Gallagher
Assembly Member Eduardo Garcia
Assembly Member Adrin Nazarian
Assembly Member Jay Obernolte
Assembly Member Bill Quirk
Assembly Member Eloise Gómez Reyes