



October 25th, 2016

The Honorable Don White
Chairman, Senate Banking and Insurance Committee
Commonwealth of Pennsylvania
286 Main Capitol
Harrisburg, PA 17120

Dear Mr. Chairman:

Thank you very much for organizing and holding a public hearing on SB 841, a bill to cap copayments and coinsurance introduced by Senator Bob Mensch (R-24th). This opportunity presents patient advocates with an opportunity to share their stories with elected officials. Maintaining access to treatments and therapies for patients with rare diseases and chronic conditions so they can remain productive citizens is an important responsibility for the Pennsylvania Senate Banking and Insurance Committee. Patient Services Incorporated (PSI) is pleased to support this important and needed legislation and urge the Committee to pass this bill.

Patient Services Incorporated (PSI) is a national nonprofit patient assistance organization that provides financial assistance to patients with rare diseases and chronic conditions such as Cystic Fibrosis, Primary Immune Deficiency, Idiopathic Pulmonary Fibrosis, Gastrointestinal Stromal Tumors and Hemophilia. PSI raises private donations and utilizes those donations to provide health insurance premium assistance, pharmacy and treatment copayments & coinsurance, as well as Medicare out of pocket expenses. PSI assists approximately 36,000 Americans with over 1,600 located in Pennsylvania.

The patients that PSI assists are middle class families battling the effects of rare, genetic conditions. Most of the copayments associated and combined with the out-of-pocket costs comprise up to 30% of the families' annual income ultimately forcing them down the arduous and devastating path to try and qualify for Medicare/Medicaid. SB 841 represents an opportunity to assist these families in Pennsylvania who are affected by rare diseases. Compliance with needed therapies is a necessity for rare disease patients to live productive lives, such as retaining employment and keeping up to date with everyday bills. Unaffordability of out-of-pocket expenses and coinsurance are drivers to the loss of healthcare access for these communities. The determination of health insurance providers to pass the costs onto the patient is leading them to potentially forgo treatment because of astronomical prices. The reduction or elimination of necessary and life-sustaining treatments leads to complications for both the patient and the Commonwealth of Pennsylvania, who will ultimately have to deal with the consequences. If patients cannot receive assistance from charities like PSI, they will make the decision to skip or reduce treatments and then turn to state and federal assistance.

The options available to these families are not optimal. Patients could attempt to obtain treatments through the emergency room system and Community Health Centers in the short term. Once that is exhausted, these families will begin the process of qualifying for the state Medicaid program, usually through the spend down process if they meet the program criteria which is different from state to state. Finally, the patient could begin the process to qualify for disability and obtain Medicare benefits. These options move the cost of care to the taxpayer while in certain instances leading to inefficient and costlier care. The approach that SB 841 takes caps the copayment for patients per prescription/per month at \$100.



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I am sure the committee has concern regarding any potential correlation between specialty tier legislation that has passed in any state and increased health insurance premiums in that state. There is no evidence that placing caps on copayments lead have any correlation to premium increases. Insurance premiums are increasing regardless of this legislation, and capping copays could lead to the reduction in costs for hospitalizations due to noncompliance, decreases in Medicaid costs, and the postponement of Medicare costs through disability.

SB 841 will strengthen coverage for patients and assist them when accessing needed treatments and therapies. This legislation also prevents increased usage of state and federal coverage programs relying on taxpayers. PSI again urges the Committee to move SB 841 expeditiously for the sake of families across Pennsylvania that struggle to afford the coverage and treatments they depend on. If you have any additional questions, please do not hesitate to contact me directly at 804.521.7908. Thank you for your time and attention to this request.

Sincerely,

Dana Kuhn, Ph.D.
President and Founder