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MASSACHUSETTS PATIENTS, HEALTH CARE PROVIDERS, AND ADVOCACY GROUPS URGE LAWMAKERS TO STOP HEALTH INSURERS FROM DOUBLE DIPPING

PROPOSED LEGISLATION WILL ENSURE COPAY ASSISTANCE COUNTS TOWARDS DEDUCTIBLES AND OUT-OF-POCKET MAXIMUMS

BOSTON--Patients, patient advocacy organizations, and health care providers today urged lawmakers on the Joint Committee on Financial Services to support two bills (<u>H.953</u> and <u>S.609</u>) aimed at eliminating copay accumulator programs in the Commonwealth.

When patients receive third party copay assistance to help offset the costs of their medications, those dollars used to count towards the patient's deductible and maximum out-of-pocket costs. But more and more insurers are no longer doing that. Instead, they keep the assistance dollars but fail to credit the patient's deductible --in essence, the insurer is getting paid twice. This causes patients financial hardship and may force them to skip their treatments.

Keyla Caba, an Ulcerative Colitis and Crohn's Disease patient from Lawrence told lawmakers she was surprised when that happened to her. Caba was prescribed a self-injectable biologic medicine, that would cost \$500 out of pocket each month because of her high deductible health care plan. The manufacturer provided copay assistance and Keyla only had to pay \$5 out of pocket. But her insurer suddenly, and quietly, implemented a co-pay accumulator adjustment program and took the \$495 of assistance but no longer counted it toward her deductible. Keyla was required to pay more out of pocket and never actually met her deductible.

"It really goes against the grain of what insurance is for. We all pay our insurance premiums. In return, I expect my insurer to be transparent and play by the rules. I do not expect them to take that money and leave me hanging," Caba said. "Assistance meant to help patients should do just that. It should not be used to pay insurers twice."

"If patients with Multiple Sclerosis can no longer have copay assistance count toward their out-of-pocket costs, their current medications may become unaffordable. They will likely be forced to less effective treatment options," said Marissa Shackleton, Executive Director of The Elliot Lewis Center, a comprehensive care center for patients with Multiple Sclerosis. "Copay assistance allows patients to access medications, as prescribed by their doctor without worrying about the financial impact of treatment. Treatment decisions should be made between the physician and the patient, not dictated by the insurance company. Support of this bill ensures the funds designed to help patients afford treatment do just that, and not go to the insurance companies who are looking to get paid twice."

More than 50 patient advocacy and provider organizations have joined with Patients for Prescription Access to urge support for this legislation.

"Accumulators are in roughly <u>80 percent</u> of commercial health plans and they can be difficult to spot since they are buried in long, dense plan documents and under deceptive names such as "out-of-pocket protection plans" or "specialty copay solutions." said Rich Pezzillo, Executive Director of the <u>New England Hemophilia Association</u> and chair of Patients for Prescription Access. "Their impact is unmistakable and exceptionally harmful for people with high-cost conditions like hemophilia, for which there are no generic treatments, because they can force subscribers to pay their entire OOP maximum early in the year with one of their first prescription fills. And very few individuals can pay \$8,550 upfront. These new insurance practices are egregious."

"This is simply a case of greed on the part of health insurers. They are not putting the needs of patients first and foremost, and so we need lawmakers to act to ensure that patients are protected," said Bill Murphy, Director of Advocacy and Public Policy for Epilepsy, New England. "The goal of copay assistance programs is to support patients and keep them on their treatment regimen to stave off disease progression. Many times, the first a patient hears of them is when they go to pick up a prescription. We've heard stories of them leaving without their medications because they couldn't afford them. Patients are already vulnerable and stressed and for insurers to take financial help that's meant for patients is just wrong."

"Copay accumulators do not just harm patients' wallets; they undermine their access to life-saving prescription medicine, making it even more difficult for people living with ALS and other complex medical conditions to adhere to a treatment plan," said Danielle Adams, Managing Director, Advocacy (New England) for the ALS Association. "The average person with ALS lives between 2-5 years. Adhering to their medication helps extend their lives and the time they can spend with loved ones. Imagine someone with this devastating diagnosis deciding to skip their medication simply because they could not afford the copayment, while the insurer is effectively paid twice."

According to a report by the MA Health Policy Commission, out-of-pocket responsibility has been rising and will likely continue to do so in the future. And studies have shown

there is no statistically significant change in health insurance premiums increases when use of copay assistance is allowed.

Seventeen states and Puerto Rico have already passed accumulator laws to protect patients.

A recent <u>report</u> from Pioneer Institute in Boston highlights the harmful effects of copay accumulators on patients, and how hospitals and PBMs profit from implementing them.

Patient groups are hoping that the committee issues a speedy favorable report so the bill can wind its way through both branches and onto the Governor's desk.

Patients for Prescription Access members supporting the bills include:

Alliance for Patient Access

ALS Association

American College of Gastroenterology

Asthma and Allergy Foundation of America, New England Chapter

Association for Clinical Oncology

Amyloidosis Foundation

Arthritis Foundation

Coalition of State Rheumatology Organizations

Crohn's & Colitis Foundation

Epilepsy Foundation New England

Everylife Foundation

Family Reach

Fenway Health

Gaucher Community Alliance

Global Healthy Living Foundation

Headache and Migraine Policy Forum

HeartBrothers Foundation

Heart, Faith & Strength

HIV & Hepatitis Policy Institute

Infusion Access Foundation (IAF)

International Foundation for AiArthritis

Lupus and Allied Diseases Association, Inc.

Massachusetts Academy of Dermatology

Massachusetts Association for Mental Health, Inc.

Massachusetts Gastroenterology Association

Massachusetts Independent Pharmacists Association

Massachusetts Pain Initiative

Massachusetts Society of Clinical Oncologists

Meghan's Light

Multiple Sclerosis Association of America

National Eczema Association

National Hemophilia Foundation

National Infusion Center Association (NICA)
National Multiple Sclerosis Society
National Psoriasis Foundation (NPF)
Neurofibromatosis Northeast
New England Bleeding Disorders Advocacy Coalition
New England Hemophilia Association
Patients Rising
Patients Rising Now
Rare New England
Susan G. Komen
U.S. Pain Foundation

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