

Patient, Provider, and Consumer Groups Concerned About Emerging Insurance Practice That Could Lead to Higher Out-of-Pocket Costs

Washington, D.C., July 24, 2018 — A group of 58 patient, provider, and consumer organizations are sounding the alarm about an emerging insurance practice that affects how a drug manufacturer co-pay card is applied to a patient's deductible. New accumulator adjustment programs prohibit co-pay dollars from counting towards a patient's deductible, leaving many with unexpectedly high costs. In response, a coalition of organizations sent letters to every state insurance commissioner asking them to investigate.

Traditionally, co-pay cards apply to the insurance deductible, allowing patients to afford the drugs and regular medical treatment they need throughout the year. In many cases, there is little to no disclosure to the patient about their enrollment in a co-pay accumulator program, and patients are often unaware they are enrolled until asked to pay the full cost of their drug at the point of sale.

For patients who rely on expensive innovative drugs, including biologics, having to "co-pay it again" can force them to abandon their therapy, which can lead to worse health outcomes and higher health care costs, such as extended hospital stays. Patients with chronic diseases need continuous access to treatments to stay healthy.

It is critical that patients are made fully aware of the terms and scope of any health care policy by which they are impacted. We urge state insurance commissioners to investigate this new practice and welcome the opportunity to work with all regulators, policymakers and health care stakeholders to find solutions to ensure patients can access these critical medications.

A sample letter accompanies this release.

July 2018

RE: Copayment Accumulator Programs

Dear Commissioner:

On behalf of the undersigned patient, provider, and consumer organizations, we write to request that you initiate an investigation of an emerging practice being implemented by various health insurance plans, pharmacy benefit managers, and employers that prevents any copayment assistance that may be available for high cost specialty drugs from counting towards a member's deductible or maximum out of pocket expenses. Each health plan calls it something slightly different, but it is generally known as a copay accumulator adjustment program, and it is a significant concern for the communities we represent.

Many patients with chronic and rare diseases are vulnerable and depend on copayment assistance programs for their specialty medications. This new practice of copay accumulator adjustment, coupled with the rise of high deductible health plans (which are plans with deductibles of at least \$1,350 for an individual), and coinsurance, makes it difficult, if not impossible, for patients to adhere to their treatment plan.

Additionally, it is concerning that many of these plan changes have been implemented with little to no notification to the member. For those patients that do receive notification, the language can be difficult to understand, even for the most seasoned of healthcare experts. Further, some notifications mislead patients into believing that they will be protected. Patients, therefore, may not truly understand what is happening until they arrive at the pharmacy to pick up their prescription and find out that they must pay for the full cost of the drug as the copay assistance they received did not count towards their deductible. As a result, many patients could be forced to walk away without their medication. Indeed, our groups are beginning to collect patient stories in which patients indicate they did not receive a notification, or if they did, it was either not in language or a manner that was clear.

One of the challenges facing people with HIV, rheumatoid arthritis, cancer, hemophilia, multiple sclerosis, and other complex diseases is how frequently the vast majority of medications used to treat these diseases are placed on the highest cost-sharing tier. In many cases, there are only a few therapies available to treat patients with a chronic or rare condition, and it is incredibly unlikely that those few therapies have a therapeutically equivalent alternative. In the absence of copayment assistance, these individuals are often unable to afford their treatment. Biologics and other specialty therapies are often the only option for effectively treating these diseases, making affordability and access to these therapies critical.

We are deeply concerned about the issues mentioned above and the risks they pose to many patients with chronic and rare diseases. Together, as one voice, we again urge you to undertake an investigation into these practices in order to ensure patients can afford their medications.

Sincerely,

Alliance for Patient Access
Alpha-1 Foundation
American College of Rheumatology

American Kidney Fund
Arizona United Rheumatology Alliance
Arkansas Rheumatology Association

Arthritis Foundation
Association of Women in Rheumatology
Bleeding Disorders Alliance Illinois
Cancer Support Community
Cancer Support Community Arizona
Cancer Support Community California Central
Coast
Cancer Support Community Central Indiana
Cancer Support Community Delaware
Cancer Support Community Greater St. Louis
Cancer Support Community Los Angeles
Cancer Support Community North Texas
Cancer Support Community San Francisco
Crohn's and Colitis Foundation
Coalition of State Rheumatology Organizations
Colorado Rheumatology Association
Dermatology Nurses Association
Florida Society of Rheumatology
Gilda's Club Chicago
Gilda's Club Madison
Gilda's Club Middle Tennessee
Gilda's Club South Florida
Hemophilia Federation of America
Immune Deficiency Foundation
Infectious Diseases Society of America
International Myeloma Foundation
Kentuckiana Rheumatology Alliance
Lupus Foundation of America

Massachusetts, Maine, New Hampshire
Rheumatology Association
Michigan Rheumatism Society
Mississippi Arthritis and Rheumatism Society
Multiple Sclerosis Association of America
National Hemophilia Foundation
National Organization for Rare Disorders
National Organization of Rheumatology
Managers
National Viral Hepatitis Roundtable
New York State Rheumatology Society
North Carolina Rheumatology Association
Ohio Association of Rheumatology
Oregon Rheumatology Alliance
Ovarian Cancer Research Fund Alliance
Patient Access Network (PAN) Foundation
Retire Safe
Rheumatology Alliance of Louisiana
Rheumatology Association of Iowa
Rheumatology Association of Minnesota and
the Dakotas
Rheumatology Nurses Society
South Carolina Rheumatism Society
The AIDS Institute
Veterans Health Council
Vietnam Veterans of America
West Virginia Rheumatology State Society
Wisconsin Rheumatology Association