

## **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