

February 1, 2022



UTAH RARE DISEASE ADVISORY COUNCIL (RDAC)

POLICY STATEMENT

COPAY ACCUMULATOR PROGRAMS

Issue

Copay accumulator programs are a component of some health insurance plans that may affect a patient's out-of-pocket costs. They typically target specialty drugs for which a manufacturer or other third party provides copay assistance to the patient. Many patients, including rare disease patients, receive copay assistance to help pay for their medications, which are frequently high-cost and long-term.

However, such insurance company accumulator programs prevent copay assistance from applying to a patient's health insurance deductible and coinsurance. Consequently, patients who depend on this support must pay the full co-pay or deductible despite a third-party having already paid it on their behalf. This results in unnecessary financial hardship and increases the likelihood of treatment non-adherence, which can lead to a more advanced disease state.

Rare diseases are rare individually, but as a group they are more common than many people think – **an estimated one in ten Utahns, or over 300,000 women, men, and children are suffering from a rare disease.** If you don't yourself have a rare disease, you likely know a family member or friend with a rare disease – whether it is an immune deficiency, a rare cancer, or a genetic disorder in a child.

The RDAC focuses mostly on challenges shared by many people across the spectrum of rare and undiagnosed diseases. One such challenge is that for these diseases, when treatable (and not all are), medical care is **chronic and costly.**

This is where the burden of copay accumulator programs become clear. Many families have deductibles of thousands of dollars and may also have significant copays or coinsurance. When financial assistance is provided to these families to help meet these deductibles and out of pocket costs so that individuals can access proven interventions, it is important that these subsidies be allowed. However, under some insurance policies, such payments do not count towards the patient's financial obligations. Instead, patients are still required to meet their deductibles or copays regardless of third-party assistance.

The burden is significant – families, especially those with members who have rare diseases with high treatment costs, have to make decisions about whether to delay or postpone visits and care based on achieving their respective deductibles. **Applying copays derived from all sources, out of pocket copays and copay assistance programs, to insurance deductible would enable families to meet their financial obligations with minimal interruption of care.**

RDAC Position

The RDAC believes that copay accumulator programs impose a considerable burden on the community of people with rare diseases, adversely impacting their health and well-being. The RDAC recommends banning copay accumulator programs in the State of Utah.

About the RDAC

The RDAC was formed under H.B. 106 during the 2020 legislative session of the Utah Legislature (Utah code 26-1-41) to inform and advise the Utah Department of Health and the Utah Legislature regarding issues confronting individuals with rare diseases. The council consists of rare disease patients, advocates, physicians and healthcare providers.

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