How **Alternative Funding Programs** Harm Rare Disease Patients

People with rare diseases deserve timely access to care for their condition. But alternative funding programs are a new threat to rare disease patients' access.

Alternative Funding Programs

Alternative funding programs can undermine treatment of rare diseases. Third-party vendors persuade employers to remove specific specialty medications from a formulary and classify them as "non-essential" benefits. Despite having insurance coverage, impacted patients are effectively uninsured for the medication they need.

Instead, they are directed to patient assistance programs, which are intended to help disadvantaged, underinsured or uninsured patients. These funds often have limited assistance to offer, pitting insured patients against truly needy patients.

These patient assistance programs may also carry income restrictions, which make it difficult for some employed and insured patients to access their treatment.

The Risks for Rare Disease Patients

More than 95% of rare diseases do not have a treatment. For the few that do, those treatments have often been developed and approved specifically for the rare condition, and may be considered specialty medications.

Alternative funding programs target these specialty medications, which are oftentimes an integral part of a rare disease treatment plan. This can lead to treatment delays as patients navigate the complexities of alternative funding programs while also trying to learn about, monitor and treat their rare condition. These treatment delays can lead to disease progression, higher patient costs, and additional doctors' visits.

Alternative funding programs can leave rare disease patients feeling trapped. They are forced to navigate a complex paperwork game despite have insurance, all while managing their rare condition.

Protecting Patient Access

Treatment delays can be debilitating and dangerous for people with rare conditions. Policymakers must restrict alternative funding programs to protect patients and ensure they can access treatment in a timely manner. **People with rare diseases deserve timely access to treatment and complete coverage from their health plan.**

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