

Access to Routine Care and Treatments

⚠️ PROBLEM:

Variation in insurance coverage for rare diseases can obstruct patients from receiving life-altering therapies.

These include:

- cost to patients (e.g., copayments, coinsurance);
- utilization management mechanisms (e.g., prior authorization, step therapy and specialty tiers);
- provider network coverage which can delay/obstruct access to care as patient transitions from one health plan to another;
- coverage policies that restrict access to certain disease subpopulations;
- discriminatory use of quality-adjusted life year metric for rare disease treatments.



DEFINITIONS

Prior Authorization: A requirement imposed by your health insurer or plan that a health care service, treatment plan, prescription drug, or durable medical equipment prescribed by a provider must be deemed medically necessary by the plan before a patient has access to it. A health insurance or plan may thus require preauthorization for certain services before you may be able to receive them. There can be different processes in place for prior authorization in emergency versus non-emergency situations.

Step Therapy: A process used by health insurers to control costs by requiring patients to try one or more less medications specified by the insurance company, typically a generic or lower cost medicine, to treat a health condition. Patients must then fail on the medication(s) before allowing a “step up” to another medicine that may be more expensive for the insurer.

Specialty Tiers: A category of medications that requires you to pay co-insurance, or a percentage of the entire drug price.

Out-of-Pocket Expenses: Expenses for medical care that aren't reimbursed by insurance. Out-of-pocket costs include deductibles, coinsurance, and copayments for covered items and services plus all costs for items and services that aren't covered.

In-Network: Providers or health care facilities that are part of a health plan's network of providers with which it has negotiated a discount. Insured individuals usually pay less when using an in-network provider, because those networks provide services at lower cost to the insurance companies with which they have contracts.

Out-of-Network: Physicians, hospitals or other healthcare providers who do not participate in an insurer's provider network. This means that the provider has not signed a contract agreeing to accept the insurer's negotiated prices.

Centers of Excellence: Specialized programs within healthcare institutions which supply exceptionally high concentrations of expertise and related resources centered on particular medical areas and delivered in a comprehensive, interdisciplinary fashion.

SOURCES

1. Access to Critical Therapies White Paper <https://globalgenes.org/resources/guiding-principles-of-rare-disease-care-and-patient-access/>

ABOUT US

Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission we connect, empower, and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf -- helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve the more than 400 million people around the globe and nearly 1 in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact Global Genes at 949-248-RARE or visit our resource hub at globalgenes.org.

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