ACCESS TO ROUTINE CARE AND TREATMENTS

SOLUTION:

- Ensure Medicaid and its contracted managed care organizations cover a drug to its medically accepted indication as is required by federal statute.
- Ensure treatment is indicated for the specific patient population and is incorporated in the drug review process to inform appropriate drug coverage policy.
- Incorporate the patient voice into drug coverage reviews and policy formulation.
- Publish drug coverage policies so all stakeholders are informed of a plan's coverage policy.
- Cap out-of-pocket expenses for Medicare and Medicaid beneficiaries who suffer from a rare disease.
- Limit the number of prior authorizations to one per year and aim to streamline across plans for clinician prescribed treatments and services.
- Ensure healthcare providers have authority to override the step-therapy protocols if they believe that the step-therapy protocol will be ineffective, cause an adverse reaction, or physical harm to the patient, or is not in the best interest of the patient.
- Require plans have an expedited step-therapy override process in place in case of medical or public health emergencies.
- Require specialty pharmacies to report delays to patients if they will miss one life-saving dose.
- In circumstances where a patient has changed insurance plans, prohibit the new plan from requiring a step-therapy protocol already completed under their previous plan.
- Prohibit insurance plans from using adverse tiering as a method to discourage patients from accessing therapies that they need if: there are no other available treatments for their condition; the patient has failed other, less expensive therapies; their clinician has overriden a step-therapy protocol; or the treatment in question is considered a first in line therapy.
- Prohibit the use of the QALY to inform payer coverage decisions or the use of such data points as part of coverage review discussions.
- Encourage rare disease patients seek treatment at Centers of Excellence, even if out of state.

SOURCES

1. Chambers JD, Panzer A, Kim DD, Margaretos NM, Neumann PJ. Variation in US private health plans' coverage of orphan drugs. Am J Manag Care. 2019;25(10):508-512.
2. SSA § 1927 (k)(6) and Federal Register 81 at 27553 (May 6, 2016)
3. Acess 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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