

for Rare Disease Patients

More than 95% of rare disease patients don't have an approved treatment.





However, accessing these treatments can be challenging due to coverage barriers and shortsighted value metrics.





Decisionmakers can take steps to help rare disease patients overcome access barriers by:



Removing harmful utilization management practices



Incorporating patient and
Clinician perspectives in drug
pricing decisions



Eliminating discriminatory metrics, like the QALY, that don't consider individual patient needs

Cut the red tape.
Patients with rare
diseases can't wait.

