Out-of-pocket costs can put treatment out of reach for people with rare diseases.

Health plans may use specialty tiers to limit coverage for rare disease treatments.

Patients may be required to pay co-insurance, a percentage of the medication’s total cost, rather than a flat co-pay.

High out-of-pocket costs may require patients to choose between daily essentials and treatment for their disease.

Unmanageable cost sharing leaves rare disease patients in a bind.