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A LIFELINE FOR RARE DISEASES

Creating a National Risk Pool to Make High-Cost Cell and Gene Therapies Accessible

Cell and gene therapies are types of personalized medicines that tailor treatment to a patient's DNA. For conditions like sickle cell disease, hemophilia and spinal muscular atrophy, a single treatment can bring lasting relief where few effective options existed before. *The medical breakthrough is here. What's still missing is a sustainable way to pay for these treatments so they can reach the patients who need them.*

Millions Per Treatment

Current list prices range from $2 million to more than $4 million per treatment, with the full cost paid as a single claim rather than financed over years of care.



A Structural Mismatch

Today's health care system wasn't built for million-dollar therapies. Without a national mechanism to spread that risk, access to breakthrough treatments depends on the financing capacity of the plan a patient happens to be enrolled in.



Preparing for a Pipeline of Cures

The FDA projects 10 to 20 new cell and gene therapy approvals every year, each carrying a multimillion-dollar price tag. Translating that pipeline into patient access at scale requires a system-wide financing solution.



A System-Wide Solution

Congress should establish a national risk pool that would spread the high cost of cell and gene therapies across a broader population. This approach would ensure access to these treatments no longer depends on the size or capacity of any single health plan.

A national risk pool would:

1. Mandate participation by all payers to spread risk broadly and ensure eligible patients have access.
2. Finance treatments through per-beneficiary, per-month fees, with drug manufacturers entering outcomes-based contracts to guarantee efficacy and lower costs.
3. Be administered by an independent entity or designated administrator to maintain neutrality from industry or other special interests.
4. Limit eligible therapies to those treating the rarest conditions or carrying the highest costs.

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