Gene therapy could be revolutionary—if we can figure out how to pay for it

Dozens of revolutionary gene therapies that mend faulty strands of DNA are on their way, bringing the power to eliminate lethal childhood diseases, rare blood disorders and other severe illnesses.

Beneath the excitement about these potential cures lies an important catch: No one knows how much to charge for them.

The new therapies aim to fix the root causes of disease with a single dose, in which the correct genetic material is introduced into the patient's cells. If the treatments can replace a lifetime of conventional costly drugs, they may slash overall spending, even at multimillion-dollar prices. Yet the prospect of high costs is already stirring pushback.

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Rational prices are critical to ensure the breakthroughs get to patients who desperately need them, said Steven Pearson, president of the Institute for Clinical and Economic Review, a nonprofit whose reports on pricing have gained influence in the debate over U.S. drug spending. If they're too low, it could deter investment, while exorbitant costs would strain health networks.

"We have to create a system that means we don't have a speeding freight train hitting a brick wall, and really high prices that seem disconnected from the value to patients," he said in an interview. Without that, "it's likely the system will freeze up."

Read full, original post: Gene Therapy Was Hailed as a Revolution. Then Came the Bill