

## Can we afford gene therapy's million-dollar price tags?

[4-year-old] Caspian was born with a rare, inherited eye disorder called Leber congenital amaurosis, which results in the progressive deterioration of the retina, the tissue at the back of the eye that detects light and color. He could lose all vision by the time he's a teenager.

This month Caspian became among the first patients in the country to receive a new [gene-therapy treatment called Luxturna](#).

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The therapy entails inserting a functional gene through harmless, virus-like particles into the retinal cells to compensate for the faulty gene causing his disease.

It's among the most expensive treatments on the market, with a [price tag of \\$850,000](#) to treat both eyes, raising questions about how the health system will absorb such treatments as they become more common.

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The Institute for Clinical and Economic Review, an independent nonprofit that conducts cost-effectiveness analyses on new therapies, concluded in a February analysis that Luxturna's price [exceeds commonly cited thresholds](#) for cost-effectiveness, in part because its long-term benefits remain unknown.

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Spark is offering a rebate of up to 20% if the therapy doesn't work in 30 to 90 days and again 2½ years later, [Spark CEO Jeff] Marrazzo says. It also is offering to pay patient out-of-pocket costs, including copayments. "Of course we're going to continue to push to get patients more access, but we're pleased with the start," he says.

*Editor's note: Full text behind paywall*

**Read full, original post:** [High Hopes for a Gene Therapy Come With Fears Over Cost](#)