

## Paying for pricey gene therapy without insurance: Amish community faces challenge

[A]t \$850,000 a person, [Luxturna](#) was more budget-busting than just about any other drug.

[Company] Spark had proposed a few different ways of [helping insurers to cover the gene therapy](#) — but Dr. Kevin Strauss' patients tend not to have insurance. As the medical director of the Clinic for Special Children, on the outskirts of Strasburg, Pa., he mostly sees members of the Plain community: Old Order Amish and Mennonite families, who believe that caring for the sick and the elderly is a community's responsibility.

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[T]wo Amish girls have a mutation in the RPE65 gene, causing the specific form of [retinal blindness](#) that Spark's therapy is designed to treat. There is no way the parents would get Luxturna for only one of them, while letting the other's vision fade even further.

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For now, Strauss feels that the parents have no good options. "The family can break with tradition ... and sign up for Medicaid," he said. "It's a repugnant idea to them, but you're choosing between that and watching your children go blind."

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It's a strange kind of diplomacy to unfold in a rural clinic, trying to untangle the economics of something unquantifiable. The parents are still optimistic. They're waiting, checking in with both Spark and Strauss, hoping some deal can be reached, hoping to restore their daughters' sight.

**Read full, original post:** [The Amish pool resources for their medical care. A budget-busting gene therapy puts them in a bind](#)