

FOR IMMEDIATE RELEASE
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Fighting Blindness Canada urges Provinces to Sign Agreement for Sight-Saving Treatment

TORONTO, ON —Fighting Blindness Canada is pleased to hear the announcement that Canadians are one step closer to accessing Luxturna® (generic name: voretigene neparvovec)¹, a sight-saving gene therapy. The pan-Canadian Pharmaceutical Alliance has concluded price negotiations with the manufacturer for this groundbreaking treatment, which is aimed at Canadians losing sight due to inherited retinal diseases (IRDs) retinitis pigmentosa and Leber congenital amaurosis, caused by the RPE65 gene mutation. However, this treatment will not be accessible to all Canadians until one final step is completed: approving Luxturna for public funding through each province’s and territory’s health care coverage.

“Living with an IRD has a significant socio-economic and emotional impact not just on the individual but also their entire family,” said Doug Earle, President & CEO of Fighting Blindness Canada, citing a recent IRD Counts study that found the socio-economic impact for Canada with IRDs is \$1.6 billion. Eighty percent of this cost is borne by the individuals and their families.¹

“Having access to a treatment that can help slow or stop progression of vision loss is life-transforming. This is the only treatment available for these individuals and we are asking Canada’s provinces and territories to recognize the hope Luxturna represents to restore sight and prioritize its access.”

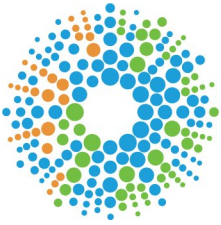
“We’re calling on each provincial and territorial government to immediately sign the agreement to cover the cost of this treatment. It has been almost two years since Health Canada approved Luxturna, yet the individuals who desperately want this treatment still don’t have access to it and have been needlessly losing sight each day,” said Earle.

Fighting Blindness Canada is urging all Canadians to visit [ApproveLuxturna.ca](https://www.approveluxturna.ca) to send an email to their Premier and Health Minister to expedite access to Luxturna.

“Canadians have waited long enough,” Earle stated. “It’s time to act now to ensure people living with vision loss caused by the RPE65 mutation do not continue to lose sight.”

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¹ Deloitte Access Economics. The socioeconomic impact of inherited retinal dystrophies (IRDs) in Canada. Available at: <https://www.fightingblindness.ca/get-involved/helpadvocate/>



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About Fighting Blindness Canada:

Fighting Blindness Canada (FBC) is the largest charitable funder of vision research in Canada. Over our 48-year history, FBC has contributed over \$40 million in funding for the development of sight-saving treatments and cures for blinding eye diseases. Thanks to our supporters, FBC is helping drive forward research to understand why vision loss occurs, how it can be slowed, and how sight can be restored. To learn more, visit fightingblindness.ca or call 1-800-461-3331. For vision health inquiries, call 1-888-626-2995 or email healthinfo@fightingblindness.ca to reach FBC's Health Information Service.

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ⁱ Luxturna is a registered trademark of Spark Therapeutics Inc., used under license by Novartis Pharmaceuticals Canada Inc.