



**FIGHTING  
BLINDNESS  
CANADA**

**VAINCRE  
LA CÉCITÉ  
CANADA**

# THE PREVENTABLE VISION LOSS AND BLINDNESS SUMMIT

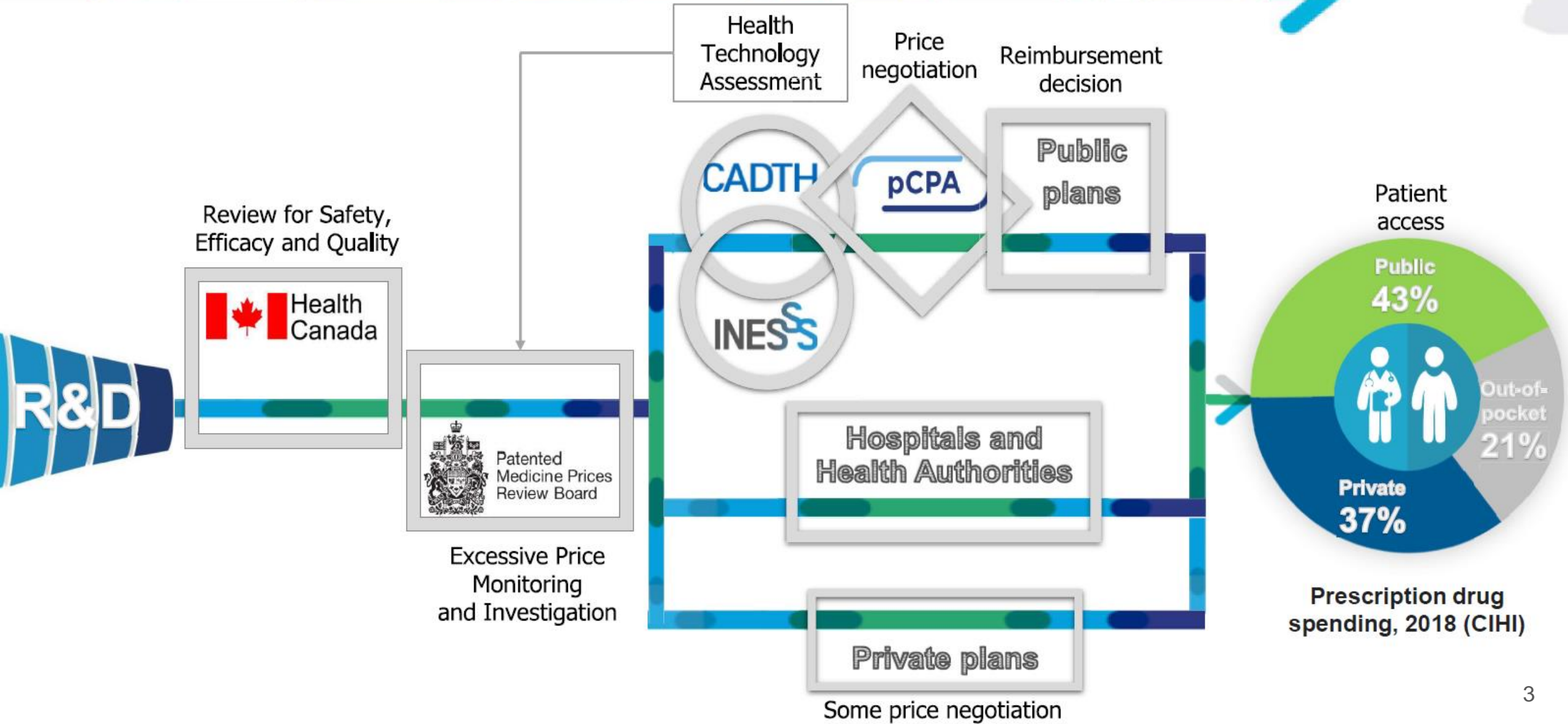
Presented by  
Doug Earle, President & CEO  
Fighting Blindness Canada

# Disclosures

- Direct Research Support: None
- Employer: Fighting Blindness Canada
- Advisory Committees  
( in the last 3 years) Roche Global; Novartis Canada;  
Janssen Global
- Consultation, Honouraria None
- Bias I live with an eye disease. I know many people living with vision loss. I'm biased.



# Canada's drug approval process reduces access



# The Luxturna journey in the world to

- December 2017 - U.S.A. Food & Drug Administration (FDA) approves Luxturna (Spark Therapeutics)
- Novartis launches outside of USA
- 25 countries authorized Luxturna as a treatment
- 6 countries considering re-imburement of treatment
  - Argentina, Brazil, Canada, Greece, Poland, Portugal
- 19 countries have re-imburement of treatment
  - Notables: UK, Austria, Germany, Croatia, Spain, France, Australia



# Luxturna's approval journey

- Health Canada receives application to approve as a treatment in Canada
- CADTH receives “patient input” May 2020 – 537 responses to survey
- Health Canada – approved as a treatment – October 13, 2020
- Recommended for public funding
  - CADTH – November 12, 2020
  - INESSS – December 2, 2020
- pan-Canadian Pharmaceutical Alliance – FBC has met them 5 times in 2021
  - “Under consideration for negotiation” since January
  - Provinces agree to try to negotiate access on November 25, 2021

p-CPA can move quickly if they want to:

- Zolgensma – approved by Health Canada December 16, 2020
  - pCPA approved October 8, 2021 -- ~\$3M



# ACCESS TO LUXTURNA ... Restoring sight gene therapy

[www.approveluxturna.ca](http://www.approveluxturna.ca)

[Home](#) [About Luxturna](#) [Treatment Approval](#) [Where is Luxturna Now](#) [Act Now](#)


**APPROVE  
LUXTURNA**





Luxturna is the world's first approved gene therapy for an inherited blinding eye disease that is turning the dream of restoring sight into a reality.

**Fighting Blindness Canada**  
Sponsored  
ID: 1044463809646680

For over 240 days, people have been going blind unnecessarily... We have an approved treatment to restore sight but is stalled with government negotiators.



**APPROVE  
LUXTURNA**



**TAKE ACTION**

[HTTPS://APPROVELUXTURNA.CA/](https://approveluxturna.ca/)  
Click 'Sign up' to send an email demanding action.

Sign Up

Almost 5200 people have sent emails = over 18,000 emails to  
Premiers & Health Ministers



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# VISION PARTNERS UNITED - TO PREVENT

- **National Vision Health Plan**

Canada has made this commitment 5 times since 2003

- World Health Assemblies meetings where Canada voted to deliver this plan:
  - Chretien - May 21 2003 56th World Health Assembly
  - Harper - May 27th 2013 66th World Health Assembly
  - Trudeau – May 18-19 & Nov.9-14 2020 73rd World Health Assembly
- Trudeau – July 23, 2021 – UN General Assembly (193 countries including Canada) unanimously supported motion “Vision Care for Everyone” by 2030

- **Vision Health Desk in Health Canada**

- **Vision Health Research strategy leveraging Canada’s strengths in research**

- Dedicated \$150 million fund in the CIHR Budget
- Renewed funding of Diabetes Action Canada – SPOR grant
- Our Report found only \$21 million being spent on vision research in 2019

SIGN THE PETITION: WE NEED A NATIONAL VISION  
HEALTH PLAN

## READ THE REPORT



[DOWNLOAD THE SUMMARY](#)

[DOWNLOAD THE FULL REPORT](#)

[www.STOPvisionloss.ca](http://www.STOPvisionloss.ca)  
[www.STOPàlapertedevision.ca](http://www.STOPàlapertedevision.ca)







CANADIAN COUNCIL  
OF THE BLIND



LE CONSEIL CANADIEN  
DES AVEUGLES



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# THANK YOU

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