

White Cane

The Voice of the Blind™ in Canada

Magazine

THE HONOURABLE

JUDY SGRO

Introduces Bill C-284
to Establish a National
Eye Care Strategy

INSIDE:

Nothing About Us, Without Us
Report Card on Vision Health
Ontarians' Access to Quality Eye Care





Here for you for the
moments that really matter

BAUSCH + LOMB
See better. Live better.

@BauschLombCA





TABLE OF CONTENTS

- 4 President's Message: The CCB's Role in Vision Health
- 6 Today's Canadian Council of the Blind
- 7 Standing with Ukraine and Honouring Our Indigenous Peoples
- 9 Editorial: Emerging From the Pandemic
- 10 2023 Person of the Year Award Recipient: Ian White
- 13 2023 President's Award Recipient: Mel Doris
- 15 Nothing About Us, Without Us
- 18 Living Well With My Glaucoma
- 19 The Honourable Judy Sgro Introduces Bill C-284
- 20 VIA Rail Charts Course for More Inclusive Travel
- 21 Report Card on Vision Health in Canada
- 23 Ontario Minister of Health Sylvia Jones Speaks on Publicly-Funded Eye Care
- 24 CCB Local Chapters
- 25 CCB Directors and Staff
- 26 Canadian Association of Optometrists
- 27 Research Develops New Therapy for Blinding Eye Diseases
- 28 AMI's Plans for Exciting Summer Programming
- 32 Seeing the World Before Their Vision Falters
- 35 Pre-COVID Perspectives on Vision Loss: What Has Changed?
- 37 Halifax Vision Loss Rehabilitation Clinic Offers Integrated Services
- 39 In the News
- 44 Canadian Ophthalmologists – Innovating for All
- 45 CNIB Steps Into the Way Forward
- 46 Thank You – We Couldn't Do It Without You

PUBLISHER

Michael Baillargeon
ambailargeon@rogers.com

EDITOR

Mike Potvin
mpotvin@ccbnational.net

SENIOR WRITER & COPY EDITOR

Tania Amardeil

CONTRIBUTING WRITERS

Jim Tokos, Mike Potvin, Michael Baillargeon, Keith Gordon, Mike Ives, Caitlyn Crews, Catherine Langlois, Lawrence Gunther, Ian White, Steve Gow, Chad Andrews, Luna Bengio, The Honourable Sylvia Jones, Caleigh Nevin, Tania Amardeil

SPECIAL CONTRIBUTORS

Canadian Association of Optometrists, Canadian National Institute for the Blind Foundation, Canadian Ophthalmological Society, Fighting Blindness Canada, Vision Loss Rehabilitation Canada

PHOTO CREDITS

CCB Outlook Library, Andre Martin, AMI Photo Library, Edith Lemay, Marion Green, VIA Rail Photo Library, Copyright House of Commons, VLRC Photo Library, Theo Euteneier

GRAPHIC DESIGN

S.O.B. Communication Design

PRINTER

Mi5 Print & Digital

DISTRIBUTION

Maria Jimena Flórez
admin@ccbnational.net

ADVERTISING AND SPONSORSHIP SALES

Michael Baillargeon
Tel: 416-651-2102
ambailargeon@rogers.com

Keith Communications Inc.
Jim Hall, President
1267 Dorval Drive, Unit: 26
Oakville, ON M6M 3Z4
Tel: 905-849-7777 Ext. 119
jhall@keithhealthcare.com

CCB NATIONAL PRESIDENT

Jim Tokos

EXECUTIVE DIRECTOR

Jim Prowse

CANADIAN COUNCIL OF THE BLIND NATIONAL OFFICE

14 Chamberlain Avenue, Suite 200
Ottawa, ON K1S 1V9
Tel: 613-567-0311
Toll-free: 877-304-0968
Fax: 613-567-2728
ccb@ccbnational.net
www.ccbnational.net



White Cane Magazine is published twice yearly in May and October by the Canadian Council of the Blind under the direction of Keith Communications Inc. The publisher accepts no

responsibility for advertiser claims, unsolicited manuscripts, photographs, transparencies or other materials. No part of this magazine may be reproduced in any form without the written permission of the publisher. White Cane Week™ and the Voice of the Blind™ in Canada are registered trademarks of the Canadian Council of the Blind. Copyright © 2023 by the Canadian Council of the Blind. All rights reserved. Proudly printed in Canada.

President's Message



PHOTO BY: **ANDRE MARTIN**

Every year at this time, the President of the Canadian Council of the Blind (CCB) gives an update on what activities the CCB has been involved in over the previous year. This year, I'd like to report on the state of vision health in Canada and describe the leadership role that the CCB has taken in delineating this.

It all started in 2020, when we released what we regarded as the most consequential study on the prevalence and cost of vision loss in Canada conducted since 2009. The previous study of this sort had been conducted in 2009 using 2007 data. The 2020 study was conducted in partnership with Fighting Blindness Canada (FBC) and key partners the Canadian Association of Optometrists and the Canadian Ophthalmological Society. The results of the study were reported in an article in the March 2022 edition of *White Cane Magazine*. The key findings of the study revealed that there were 1.2 million Canadians living with vision loss and a further 8 million who had a potentially blinding eye disease. The study went on to estimate the total cost of vision loss in Canada in 2019 at \$32.9 billion, which consisted of a total financial cost of \$15.6 billion and a loss of well-being cost of \$17.3 billion. A subsequent addendum to the 2020 study conducted in 2021 looked at the impact that the COVID-19 pandemic had had on vision health in Canada. The addendum report, released in October 2021, estimated that 1,437 Canadians experienced vision loss due to delayed

eye examinations and treatments in 2020. This study reported that there were almost 3 million fewer visits to optometrists in 2020 compared with 2019, 143,000 fewer eye surgeries, and 70,000 fewer eye injections for the treatment of age-related macular degeneration and diabetic retinopathy.

In April 2020, the CCB also conducted a survey of people living with vision loss to determine the impact that the COVID-19 pandemic had had on their daily lives. Respondents to the CCB survey revealed the existence of a high level of stress, anxiety, fear, and even depression within the vision loss community. The results of this survey were released in April 2020 and were used to advocate for priority COVID-19 vaccination as well as several other issues that would improve pandemic-related conditions for people with vision loss.

In July 2021, the CCB conducted an almost identical survey of the vision loss community to that conducted in April 2020 and found that the level of stress had decreased significantly since 2020, but that there were still a significant number of people experiencing pandemic-related stress.

Fast forward to 2022: the CCB felt that it was important to reassess the state of vision health in Canada to see if the impact of the pandemic reported in 2020 had persisted through 2021. To achieve this, the CCB issued a Report Card on Vision Health in Canada, which is discussed in this issue of *White Cane Magazine* in an article by the Report Card's Principal Investigator, Dr. Keith Gordon. The Report Card showed that while backlogs in eye doctor visits and eye surgeries had decreased, neither the number of visits to eye doctors nor the number of eye surgeries had returned to pre-pandemic levels, and the wait times for eye surgery continued to grow despite the significant additional investments that governments had made to decrease these backlogs.


The CCB research I have just discussed has all pointed to one primary recommendation: the need for a national vision health strategy for Canada. I'm now pleased to be able to report that there has been progress on this front. On June 14, 2022, the Honourable Judy A. Sgro, P.C., MP, tabled Bill C-284 in the House of Commons, calling on the government to develop a national strategy for eye care. I'm proud of the role played by the CCB's research and advocacy to enable us to get to this point and am hopeful that Bill C-284 will be enacted very soon.

Speaking of advocacy, I'm also very proud of the role that the CCB has played in advocating for the reimbursement of Luxturna, the first Health Canada-approved targeted gene therapy for any disease and the first gene therapy treatment of an eye disease. Luxturna is a treatment for people who have a very rare genetic disorder – either Leber congenital amaurosis or retinitis pigmentosa caused by mutations in both copies of the RPE65 gene. There are very few people in Canada, around 40 presently identified, who are candidates for this sight-saving treatment. The CCB and our partners

had to advocate at every stage of the complex process used in Canada to gain approval for new treatments.

As of the time of this writing, five provinces – Quebec, Alberta, Saskatchewan, Ontario, and Nova Scotia – have approved reimbursement for the treatment. Luxturna is effective in restoring night vision and stopping further vision loss. For those children who have accessed this innovative treatment, it is the gift of sight and life-transforming. Most gratifying for all involved is the fact that for the first time in their lives, they can see the stars.

Finally, I would like to tell you about the CCB conference (you're invited) that will take place in Ottawa on May 16th, 2023. Entitled "New Treatments for Eye Disease – a Vision of the Future," the conference will focus on the state of vision health in Canada, exploring new treatments for eye disease and a vision for the future. Subjects to be covered include new gene therapies for the treatment of eye disease, new methods for the surgical treatment of glaucoma, and new treatments for retinal diseases. Presentations on new treatments will be given by three of Canada's foremost ophthalmologists. The conference will be held both virtually and in person from 10 a.m. to 1.30 p.m. at the Great Hall, Christ Church Cathedral, in Ottawa. Registration for the conference (which is free) can be done now online through the CCB at www.ccbnational.net. I hope to see you there.



Jim Tokos
National President
Canadian Council of the Blind

Today's Canadian Council of the Blind



The CCB offers numerous programs to assist people living with vision loss, to increase accessibility in all areas of vision loss life, and to bring attention of vision issues to the general population and government. The CCB provides education and awareness in preventing vision loss by promoting healthy living and regular eye examinations. Most importantly, the CCB collaborates with service providers and all levels of government in order to improve the current levels of service regarding accessibility and quality of life.

The CCB supports initiatives that call for the provision of the very

The Canadian Council of the Blind (CCB) was founded in 1944 by schools of the blind and returning blind Canadian war veterans, and is recognized as the Voice of the Blind™ in Canada. The CCB is a membership-based not-for-profit, a nationally-registered charity, an extensive peer support network, and a consumer advocacy organization that brings together Canadians who are living with vision loss, including those who are blind, deaf-blind, and partially-sighted. In bringing together Canadians with lived experience of vision loss, the CCB maintains a vibrant network of active members in 80 chapters across Canada. Each chapter is unique to its geographic area, community-based, locally-organized, and volunteer-driven by those with vision loss, and engages in a variety of social, recreational, and community activities based on the interests of local members.

A tireless advocate of the vision loss community, the CCB works to promote a sense of purpose and self-esteem along with enabling the efforts of each member to achieve an enhanced quality of life. The CCB, through its lived experience constituency, is proud of its efforts to break down barriers and remains dedicated to building public awareness and improving the well-being of people with seeing disabilities.

best in available medical treatments. It advocates for increased funding for vision research and for research for devices and technology that improve the lives of people living with vision loss. It supports the fostering of patients' rights without limitation or discrimination. The CCB works with its vision partners Fighting Blindness Canada and the CNIB to provide a united voice for people living with vision loss in advocating for access to innovative treatments that prevent vision loss and restore sight. Together, the organizations advocated to bring anti-VEGF medications to Canada in 2006, and in the past year they advocated in support of access to two new medications to prevent blindness in people with age-related macular degeneration (AMD) and diabetic retinopathy. The CCB's advocacy has contributed to increasing access to the first new glaucoma medication in the last 20 years. This medication is now publicly-funded in eight provinces. Its advocacy also contributed to the positive recommendation made by the Ontario Health Technology Advisory Committee (OHTAC) to suggest public funding of a minimally-invasive glaucoma surgery device. The CCB also played a major role in advocating for the reimbursement of the first targeted gene therapy to restore sight for an inherited retinal disease. This sight-saving therapy is now funded in five provinces.

Over the past few years, the CCB has undertaken a number of important studies on issues that affect the lives of people living with vision loss, as well as issues that affect the vision health of all Canadians. It has produced important reports on accessible technology and assistive devices, as well as a survey of Ontarians regarding their experiences with and perceptions of the Ontario Assistive Devices Program. In the very early weeks of the pandemic, the CCB was quick to survey Canadians who are blind, deaf-blind, or partially-sighted to gain an understanding of the pandemic-related issues they were experiencing. The results of this study were released in April 2020 and were used to advocate for a number of the issues identified in the study, such as priority vaccination for people living with vision loss. In December of 2020, the CCB commissioned a study of the prevalence and cost of vision loss in Canada. It worked to deliver this report in partnership with Fighting Blindness Canada, the Canadian Association of Optometrists, and the Canadian Ophthalmological Society. The landmark report was published in May 2021. An addendum to this report, which assessed the impact of the COVID-19 pandemic on vision health, was released in August 2021, and a follow-up report card that assessed the impact that the pandemic has had on ongoing vision health in Canada was released in October 2022.

Through advocacy and research, the CCB is dedicated to building public awareness and improving the well-being and quality of life of those living with vision loss. It does this to ensure that stakeholders, governing bodies, and members of the vision loss community are informed with data that is substantive and reflective of the needs of all Canadians living with vision loss. The CCB does this all while recognizing that most vision loss and blindness can be prevented or treated.

The CCB is supported by its members, volunteers, and donors, who contribute collectively over 30,000 hours of their time on an annual basis to help achieve the success of the CCB's programs and initiatives.

For more information about the CCB, please visit www.ccbnational.net.



The Canadian Council of the Blind Stands with Ukraine

The Canadian Council of the Blind would like to express its deep concern and support for the people of Ukraine – in particular, our brothers and sisters in the blind, deaf-blind, and partially-sighted community, including members of the Ukrainian Association of the Blind.

The Russian military assault on Ukrainian cities has taken the lives of innocent civilians. This unjustified war is a crime against humanity, violating all norms of international humanitarian law. We further urge the European Blind Union and its members in Europe to continue to provide all possible assistance and accommodation to refugees from Ukraine with visual disabilities.

Honouring the Algonquin Anishinabe Nation, First Nations, Inuit, and Métis Peoples

The Canadian Council of the Blind (CCB) acknowledges that Ottawa, home of our head office, is built on un-ceded Algonquin Anishinabe territory. The peoples of the Algonquin Anishinabe Nation have lived on this territory for millennia. Their culture and presence have nurtured and continue to nurture this land.

The CCB honours the peoples and land of the Algonquin Anishinabe Nation. The CCB honours all First Nations, Inuit, and Métis peoples and their valuable past and present contributions to this land.

Along with the Government of Canada, we at the CCB are committed to a renewed nation-to-nation relationship with Indigenous peoples based on recognition of rights, respect, co-operation, and partnership.



Better is
**seeing what
matters**

We are committed to helping reduce the number
of people impacted by visual impairment.

Science for better

COR-EYL-CA-0017-1



The Disabled Community Is Emerging From the Pandemic One Step at a Time, With Heads Held High



PHOTO BY: **ANDRE MARTIN**

To say that the last three years have been challenging is a bit of an understatement. The global population collectively went through a traumatic experience, and although things are getting much better, we're still learning how to navigate this new reality.

A crisis like the pandemic sheds light on the weak points of our social systems and exposes the fragility of the institutions that we rely on. Marginalized individuals are at a higher risk of becoming even further marginalized as economic disparities are exacerbated.

This is especially true for persons living with disabilities. Throughout the pandemic, the issues faced by society were amplified for those of us in the disabled community. I'm sure we can all remember constantly judging our distance from one another in public spaces and attempting to stay the suggested six feet apart – an incredibly challenging task when one could not see the individuals whom we were trying to maintain a distance from.

And that's just one small example. Social gatherings, which are so integral to peer support, were no longer possible, and important programs related to independent living were curtailed. This put members of the disabled community at greater risk of social isolation as support systems seemed to vanish in an instant.

Fortunately, organizations such as the Canadian Council of the Blind (CCB) reacted quickly, moving social gatherings online as we all adapted to the new reality of Zoom. Programs such as the CCB's Get Together with Technology (GTT) leaped into action and quickly taught individuals living with vision loss how to capitalize on their assistive technology so they could participate online. People who had never used a smart phone before began talking to friends

and family all across the country, face to face again, albeit virtually.

Fast forward to today, and things are looking up. Many groups have moved back to in-person gatherings again, and the majority of support systems have returned. Programs such as the CCB's GTT are going stronger than ever and continue to share information on accessible technology amongst peers. It has been wonderful connecting with friends and colleagues and just feeling that sense of normalcy.

This is why it's so important to remain vigilant, to continue to advocate for our rights, and to be treated as equal citizens. White Cane Week provides an excellent opportunity to raise awareness of the needs of the visually-impaired community, as well as to showcase our many abilities.

I'm hoping White Cane Week will look much more like we're used to next year. Please join me to continue to support our peers, demonstrate all the things we're capable of doing, and trust in ourselves that we will always overcome any challenge put in our way.

A handwritten signature in black ink that reads "Mike Potvin". The signature is stylized and cursive.

Mike Potvin
Editor

Ian White Named the 2023 Person of the Year

This year, the Canadian Council of the Blind (CCB) is pleased to present the Person of the Year Award to Ian White, a fierce advocate for the visually-impaired community and a shining example of how an individual with vision loss can achieve their full potential.

Born with congenital glaucoma in Northwestern Ontario, White was raised, sighted, in Vancouver, B.C., and Oakville, Ont., moving to Toronto in 1981, where he completed a Bachelor of Applied Arts at Ryerson's School of Interior Design (now called the Toronto Metropolitan University School of Interior Design). White worked as a designer and senior project manager for one of Canada's premier corporate design firms. He continued to pursue a career in corporate design until 2001, when vision loss prevented him from continuing in the design sector. White's vision had gotten progressively worse due to surgery complications, ultimately resulting in him going blind.

"How does one describe utter devastation?" says White. "My professional development and personal interests were all centered on what I could see, from my design career to my interest in art and architecture to my hobbies of reading and travelling. Beyond all that, the catastrophic thing for me about losing my vision was that every means I had for defining myself was based on what I could do, and what I could do was based on what I could see. When I lost the ability to see, I lost the ability to do, and so I lost my sense of self-identity."

White was forced to give up his career and struggled with relating to the people around him and with wanting to support and contribute to his family, including his four-year-old child.

"I had to re-imagine what I could do and how I could contribute," says White. "There's a complete restructuring of identity that occurs when you're faced with a seeing disability."

Fortunately, White did what needed to be done to accomplish this restructuring. He learned how



PHOTO BY: AMI PHOTO LIBRARY

to use assistive devices and technology – from a white cane to screen reader software and more – and began to engage with the world again, moving about independently and pursuing his love of reading, writing, and learning. He also began connecting with others in the vision loss community, which provided inspiration and led him down the path to greater involvement and a leadership position within the vision loss community.

In 2011, White began volunteering with the CNIB and took training as a group leader/peer mentor for the CNIB's New Beginnings program. That same year, he co-founded the Toronto Visionaries Peer Support Group, which was chartered as a Chapter of the CCB in 2013. As Chapter President, White has overseen the Visionaries' phenomenal growth and has encouraged the creation of several new CCB Chapters in the Toronto area, focused on tactile art, dragon boating, rock climbing, running, and other social and recreational activities for those living with blindness and vision loss.

"Our mandate is to get people connected with their peers," he says, "so we work on creating opportunities for people to get together and sharing information about how to navigate the world as someone with a visual impairment. We do a huge array of activities, from conversation groups, games, and book clubs



CCB Toronto Visionaries Chapter President Ian White centering CCB National President Jim Tokos and CCB Director Leslie Yee at the opening of the 2022 Experience Expo at Toronto's Miles Nadal Jewish Community Centre. PHOTO BY: MARION GREEN

to pub nights and dinners out to tours of historic sites and museums to sports, walking tours, and so much more. We also have fundraisers, like our annual Walkathon and BBQ at Woodbine Beach, and we go on special outings, whether it's a winery tour in Niagara or to Stratford to see a play."

White was responsible for creating the Experience Expo in Toronto, a White Cane Week event that is Canada's only major exposition and consumer show for those living with vision loss. The Experience Expo is an interactive, hands-on exhibition featuring dozens of exhibitors, products, and services covering every aspect of the experience of living with vision loss. It includes a Visionaries Forum (a panel discussion on a current topic facing the vision loss community) and a Community Social Dinner, all held on the same day.

In 2015, White assisted in forming, and co-organizes, a Toronto branch of the CCB's Get Together with Technology program, a self-directed user group for those interested in assistive technologies. The program provides ongoing support to those looking to harness the power of technology to assist with their day-to-day activities and increase their quality of life.

White served on the CCB's Ontario Division Council since 2016 and was the Acting Chair from 2020 to 2022. He was also a founding director of East and West Learning Connections, a not-for-profit organization devoted to multicultural learning and cross-integration in Toronto. Over the years, White has been involved in various outreach activities and advocacy initiatives with the CCB, including participating recently on a committee with the aim of improving Ontario's Assistive Devices Program. The depth and breadth of his contribution to the vision

loss community are remarkable, and were sparked by White's personal experience and extraordinary outlook on life.

"When I lost my vision, I had no idea what blind people could do because I didn't know any," says White. "With the Toronto Visionaries, the initial idea was just to offer people a variety of activities to get them in social proximity of people who shared their experience of vision loss. That generates spontaneous conversations about whatever you want to talk about, whether it's your interests, work, or leisure pursuits, which helps to break down the stereotype of what someone living with a visual impairment is capable of. And that really is the core idea behind the Visionaries – showing people that they can be whatever they want to be."

This sense of possibility – of achieving one's potential and embracing all that life has to offer – is reflected in White's words and through his tireless engagement with the vision loss community. He is fuelled by the power of personal connection, and strives to help those who are struggling to adapt to a new situation and a new way of living their life, and trying to adjust to living in a world that they no longer see the way other people do.

"I've discovered that there's very little that people with vision loss can't do if they have the right tools and training," he says. "Meeting other blind people and being inspired by them pushed me to strive to realize my potential. That's how I got involved in volunteering, which has been a huge journey of growth and learning. I've realized my own potential and the value that I can bring to helping other people with their journey."

BIOSIMILARS: A CLOSER LOOK

Since 2009, **biosimilars** have been used in Canada as high-quality treatments for a variety of serious diseases, including cancer and diabetes, and today are emerging in the treatment of vision disorders.¹

Let's focus on what they are, why they are trusted and what they mean to patients.



BIO

Biosimilars are a type of **biological medicine** (or "**biologic**"), which is a class of complex drug products that are manufactured using living cells.¹



SIMILAR

A biosimilar medicine is **highly similar** in structure to an existing biologic (called a **reference product**) and has **no clinically significant differences** to it in safety and efficacy.¹



THOROUGH TESTING AND EVALUATION

It can take **five to 10 years** to develop a new biosimilar – a process that includes **rigorous testing and evaluation** before it can be approved and prescribed to a patient.^{2,3}



Laboratory studies assess:

- **STRUCTURE**
- **FUNCTION**



Double-masked clinical studies in people assess:

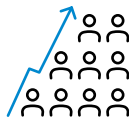
- **EFFICACY**
- **SAFETY**

A HIGH-QUALITY, MORE SUSTAINABLE ALTERNATIVE

Since they are founded on existing science, biosimilars can be offered at a lower cost than their reference biologic, which can bring **value to health systems** and **support patient access** to advanced therapies.

3.5 million

The approximate number of Canadians living with **retinal vascular disorders**, including age-related macular degeneration (AMD) and diabetic retinopathy – expected to increase as the population matures.⁴



\$863 million

The amount spent in Canada on **antineovascular medicines** that are used to treat retinal disorders – the second largest contributor to growth in public drug program spending, according to a recent study.⁵



POTENTIAL TO TRANSFORM MORE LIVES

For many people, loss of vision can negatively impact independence, employment opportunities, and cause anxiety, fear and social isolation; **biosimilars** have the potential to help more Canadians access treatment that can **preserve vision health and quality of life**.⁶

References

1. Health Canada. Drug Product Database, Accessed Feb. 2023. Available at: <https://health-products.canada.ca/dpd-bdpp>
2. Nature. Bring on the Biosimilars, May 2019. Available at: <https://www.nature.com/articles/d41586-019-01401-5>
3. Health Canada. Biosimilar biologic drugs in Canada: Fact Sheet, Accessed Feb. 2023. Available at: https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/dhp-mpps/alt_formats/pdf/biologics/apply-demande/guides/Fact-Sheet-EN-2019-08-23.pdf
4. Fighting Blindness Canada. Eye Diseases, Accessed Feb. 2023. Available at: <https://www.fightingblindness.ca/eyehealth/eye-diseases>
5. Canadian Institute for Health Information. Trends in public drug program spending in Canada, Nov. 2022. Available at: <https://www.cihi.ca/en/trends-in-public-drug-program-spending-in-canada>
6. Canadian Council of the Blind. The cost of vision loss and blindness in Canada, May 2021. Available at: <https://www.fightingblindness.ca/wp-content/uploads/2021/12/Deloitte-Cost-of-vision-loss-and-blindness-in-Canada-report-May-2021.pdf>

Doris with former Canadian Council of the Blind (CCB) president Louise Gillis, participating on a live TV broadcast attracting 38 million viewers at a medical conference on eye care in Xingtai, Hebei province, China. The CCB, with its Lions Club District A4 partners, provided Mobile Eye Clinics (MECs) for children in rural Hebei in partnership with the Hebei Provincial Eye Hospital. After visiting Norman Bethune's workplace and in his spirit, the CCB and the Hebei Eye Institute agreed to promote exchanges between the two countries on MECs.

Mel Doris

Awarded the 2023 President's Award

This year's President's Award recipient is Mel Doris, a longtime friend of the Canadian Council of the Blind (CCB) and advocate for people with low vision.

Doris began working with the CCB almost by accident – a lucky coincidence if there ever were one. “In 2003, I was asked by Jim Prowse, who had recently been appointed the CCB's Executive Director, to go over some files,” Doris recalls. “The CCB's broad objectives – awareness, prevention, and programs for the blind and those with low vision – are the same as was originally mandated in 1944. In order for the mandate to be effective, the organizational structure must be in place to implement these objectives, and over time this has been done at the CCB. I think this is the best accomplishment for the future of the organization.”

Doris' focus at the CCB soon became helping to increase awareness of the organization and improving its programming. From a hockey tour with the Flying Fathers and Walter Gretzky to the Guns

and Hoses Ball Hockey Classic tournaments to several banquets to the launch of *White Cane Magazine*, Doris helped bring to life a series of initiatives designed to elevate the relevance of vision loss and the impact of the CCB.

Doris was also instrumental in the creation of the CCB's Mobile Eye Clinic (MEC), in collaboration with Lions Clubs District A4. “Eighty percent of vision loss can be treated or prevented,” says Doris. “MECs go out into the community, to schools and seniors' homes, to help identify vision issues and correct them.” Such interventions can vastly improve patients' quality of life, improve children's educational performance, prevent slips and falls in elderly patients, and save the health care system vast amounts of money. “The recent CCB and Fighting Blindness Canada study shows the negative cost of vision loss to the Canadian economy,” says Doris. “MECs

can reduce this cost significantly and provide vision care to the underserved and underprivileged. Aside from the quality-of-life issue, prevention saves health care dollars. It makes ‘cents.’” Doris hopes to see the program expanded Canada-wide.

The President's Award acknowledges those who in their work or service with or for the blind, deaf-blind, and partially-sighted have made a real difference in improving the quality of life of the members of this community. Doris' advocacy and dedication to advancing the CCB's mission and programming are the type of boots-on-the-ground initiatives that make a real difference to the vision loss community. The CCB is grateful for Doris' longtime commitment.

“The work I've done over the years is still ongoing,” says Doris. “We're not quite where I want to be yet, but we're still moving forward.”



Focus on Geographic Atrophy

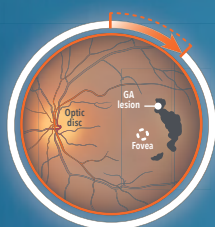
Geographic atrophy (GA) is the advanced form of dry age-related macular degeneration (AMD)^{1,2}



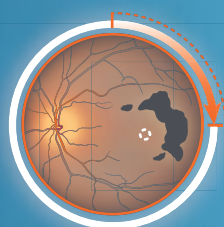
GA affects over **5 million** people worldwide³

GA affects the central portion of the back of the eye, called the macula, which is important for seeing accurate details of daily activities.² When GA spreads in the macula, it impacts peripheral and low-light vision.⁴

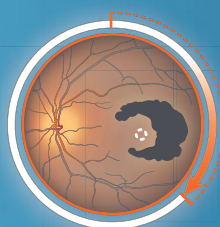
Over time, the disease may spread into the fovea at the center of the macula, which provides the central and clearest part of your vision.^{4,5}



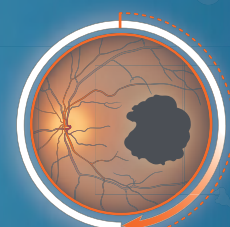
Some loss of peripheral low light vision



Loss of peripheral, low light vision



Loss of peripheral, low light vision; patches of lost central vision



Loss of central vision leading to blindness

An ethnographic study (n=16) found that GA and vision loss significantly impacts patient quality of life⁶



100% of patients reported difficulty reading



75% of patients reported difficulty with driving



63% of patients reported inability to perform household chores

References:

1. Gehrs KM, et al. Ann Med. 2006;38(7):450-471.
2. Fleckenstein M, et al. Ophthalmology. 2018;125:369-390.
3. Wong WL, et al. Lancet Glob Health. 2014;2:e106-116.
4. Boyer DS, et al. Retina. 2017;37:819-835.
5. Kolb H, et al. The Architecture of the Human Fovea. In the Organization of the Retina and Visual Systems. (University of Utah Health Sciences Center, 2020).
6. Sivaprasad S, et al. Ophthalmol Ther. 2019;8(1):115-124.

Apellis

©2023 Apellis Pharmaceuticals, Inc. All rights reserved.
04/23 MED-CA-GA-23-00003 v1.0



Nothing Without Us— The True Meaning of Inclusion

LUNA BENGIO, SENIOR ACCESSIBILITY CONSULTANT

The author Maya Angelou once wrote, “I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”

For centuries, people with disabilities have been pitied or mocked. Disability was seen as a “defect” of the individual, which should be hidden or submitted to all kinds of treatments, sound or otherwise. People with disabilities had few, if any, rights. They were institutionalized, sterilized against their will, and at best, considered as worthy of charitable efforts.

Fast forward to 1982, the Canadian Charter of Rights and Freedoms declared physical or mental disability as a prohibited reason for discrimination. This was the first time such a right was guaranteed in a country’s constitution.

When Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on March 11, 2010, it committed to rid the country of barriers that prevent people with disabilities from fully enjoying their human rights. One of the fundamental principles of the CRPD is “Nothing About Us Without Us,” which recognizes the right of persons with disabilities to play a primary role in shaping the decisions, policies, and practices that affect them.

The Accessible Canada Act (2019) (ACA) and its regulations created the opportunity to begin a robust implementation of the CRPD in Canada by transforming the way in which federally-regulated institutions are to achieve the monumental goal of a barrier-free Canada by 2040. Rather than simply relying on individuals to advocate for their right to full participation, the ACA applies the social model of disability: people are disabled by interactions with

barriers in society and the environment. Therefore, the ACA requires federally-regulated organizations to be proactive and to remove or avoid the creation of barriers to everyone’s full participation, including people with disabilities.

More importantly, and perhaps the true test of inclusion, is the fact that the “Nothing About Us Without Us” principle is embedded within the ACA. Through accessibility plans, organizations will need to demonstrate how persons with disabilities are meaningfully involved in developing and implementing these plans.

So, what does all this mean and how will we know our perspectives and our lived experiences truly count? As a blind Canadian, I’m proud of the progress we’ve made since the passage of the ACA. Accessibility is no longer such a foreign or marginal concept. In the wake of other diversity and inclusion movements, people with disabilities can now feel more comfortable speaking about the barriers they face at work or at school and expect that these barriers will be addressed. We now know that systems that work for extremes will work for everyone. Yet, too few people with disabilities are in leadership positions and consultations with users are often “checkbox” exercises that fail to empower those who can benefit the most.

“Nothing About Us Without Us” can only be exercised if decision-making processes are accessible. How can a blind person participate if information or systems are not accessible?

So, no matter what you do or your area of responsibility, always ask yourself what you can do to ensure that no one is left behind and that no one is left on the outside looking in and wondering when they can be a truly equal member of society.

If eye exams are critical to maintaining vision, why aren't Canadians getting their eyes checked?



Bill Moir
Managing Director,
Specsavers Canada

A common misconception is that good vision equates to good eye health. Unfortunately, those who believe their eye health mirrors their good vision could be putting their sight unnecessarily at risk by missing important regular comprehensive eye exams. While common sight-threatening conditions, like glaucoma, do not often show early symptoms, early diagnosis, treatment and preventative care is possible with a visit to an optometrist.

A survey conducted by Leger in 2022, showed that 1 in 4 Canadians, who do not wear corrective lenses, have not had an eye exam in at least 10 years, and 10% of Canadians who do not wear corrective lenses



Dr. Jasjit Gandham performs an eye exam on a patient.

have not had an eye exam in their lifetime. Interestingly, when Specsavers looked at why Canadians were delaying eye exams or skipping them entirely, 22% of those who do not wear corrective lenses said they did not get an exam because they didn't have symptoms of vision loss.

1 in 4 Canadians who do not wear glasses or contact lenses have not had an eye exam in at least 10 years¹

It is concerning that Canadians are waiting for vision issues as a prompt for an eye exam. When looking at glaucoma specifically, another Specsavers survey, conducted by Leger in 2023, showed that the majority of Canadians (71%) expect at least one early warning symptom of glaucoma. These statistics show the urgent need to reframe the purpose of eye exams from vision checks to a powerful tool in helping to prevent vision loss.

Our Specsavers study also showed that as many as 33% of Canadians cited cost as a reason for not getting eye exams on a regular basis. However, even

¹This includes those who have not had an eye exam in the last 10 years (14%), and those who haven't ever had an eye exam (10%).

Methodology of Canadian Eye Exam Frequency Survey (Leger Survey – September, 2022): An online survey of 1,512 Canadians was completed between September 23–25, 2022, using Leger's online panel. No margin of error can be associated with a non-probability sample (i.e. a web panel in this case). For comparative purposes, a probability sample of 1,512 respondents would have a margin of error of $\pm 2.5\%$, 19 times out of 20.

Methodology of Glaucoma and Eye Exams Survey (Leger Survey – January, 2023): An online survey of 1,536 Canadians, 18+, completed between January 6 and January 9, 2023, using Leger's online panel. No margin of error can be associated with a non-probability sample (i.e. a web panel in this case). For comparative purposes, though, a probability sample of 1,536 respondents would have a margin of error of $\pm 2.5\%$, 19 times out of 20.



Dr. Jasjit Gandham reviews an OCT scan with a patient.

Canadians without financial barriers are not getting their eyes checked. In fact, almost half (46%) of Canadians who have insurance coverage and are aware of these benefits, did not plan to use their coverage in 2022 for eye health or eyewear such as prescription glasses and contact lenses.

Our purpose is to change lives through better sight

When it comes to eye exams, there's no one-size-fits-all approach – each eye exam is tailored to each patient according to their needs. Optometrists gather as much information as possible to provide a comprehensive eye exam where they perform

specific assessments based on family history and risk factors for eye disease.

At Specsavers, our purpose is to change lives through better sight. All patients who visit an optometric practice located at a Specsavers store receive an advanced 3D eye scan – optical coherence tomography (OCT) – included in the eye exam. OCT helps optometrists see what is going on beneath the surface of the eye and can detect potentially sight-threatening conditions such as diabetes, glaucoma, and age-related macular degeneration. OCT works by taking a series of scans of the back of the eye that form a detailed 3D image of important structures in the eye, such as the optic nerve, retina and macula. These 3D scans

help optometrists spot any abnormalities and identify eye diseases in their earliest stages.

All patients receive an advanced 3D eye scan – optical coherence tomography (OCT) – as part of the eye exam

Specsavers was founded on the belief that eyecare and eyewear should be accessible to everyone, whether that is providing optometrists with technology like OCT to assist them with early detection of eye disease, or offering patients a selection of high-quality, stylish glasses and contact lenses at a more affordable cost. However, our commitment extends past our front doors and into the communities that we serve. We have a goal to significantly improve Canadians' eye health through increased vision health awareness, which we know will lead to better health outcomes.

With over 60 locations now open across Canada, find a location near you to book an eye exam at [specsavers.ca/stores](https://www.specsavers.ca/stores)

Specsavers





BROUGHT TO YOU BY A BIOPHARMACEUTICAL COMPANY.

Living Well With My Glaucoma

Geoffroy is a 41-year-old Montreal resident living with glaucoma.

When Geoffroy Gravel-Chalifour was in his late 20s, his mother was diagnosed with glaucoma. Geoffroy discovered glaucoma runs in his family. At the age of 30, he was diagnosed with primary open-angle glaucoma. With the support of his eye care team, Geoffroy began his journey with glaucoma and prioritized his goal to protect his vision and his active way of life. Today, Geoffroy's vision is stable and he continues to enjoy kitesurfing, snowboarding, golfing, and a demanding career that often takes him on the road.

How did you feel when you were told you had glaucoma? I was shocked. I was in my early 30s. I'm active. I'm healthy. I was completely caught off guard and frankly surprised. I started to search the internet and actually became even more concerned about what I saw online. It was scary. I thought, isn't this something that affects older people? But I was wrong. Since being diagnosed, I've been so pleased to meet people living with glaucoma and to realize I'm not alone. The other day while watching hockey, I met someone who is 49 with glaucoma. I thought, cool. That can be me in a decade.

Did you have any concerns about eye surgery? Microinvasive glaucoma surgery (MIGS) was

pretty new at the time. There wasn't a lot of good, accurate information easily accessible. Long-term results were unknown. But I was confident in my eye care team, my treatment plan, and my incredible ophthalmologist. Surgery was the only option for me to maintain the vision I have. Thankfully, MIGS is becoming more and more common with even greater data available.

What's it like living with glaucoma? I plan more. I give more thought to my actions. I have good vision now. My glaucoma is being controlled, so I feel like I need to live my life to the fullest. For my work – I'm a business developer who spends a lot of time on the road and interacting with people – I give more thought to what my future employment will look like. I give a lot of thought to a backup plan. What happens if/when I can't drive anymore? I think about empowering others around me and defining a role that is more coaching and mentorship-based, which is exciting and rewarding.

How do you feel about your glaucoma today? I feel good. My glaucoma is under control. My eye care team is fantastic. I interact with my ophthalmologist twice a year. I see my optometrist twice a year. This is a good frequency that works

for me. I encourage others to be proactive in their eye care health.

I was so young when I was diagnosed with glaucoma. It's important to know that you're not alone. There are so many people who have been impacted by this eye disease. Like me, you can live your life to the fullest.

Glaucoma Facts

1. Glaucoma is the second leading cause of blindness in Canada, affecting nearly 800,000¹
2. The most common form of glaucoma is primary open-angle glaucoma, with almost 90% of cases²
3. Regular eye exams are essential for detecting and managing glaucoma³
4. While anyone can develop glaucoma, there are certain risk factors that increase the likelihood of developing the condition, including age, family history, and certain medical conditions such as diabetes and high blood pressure⁴
5. Treatment for glaucoma aims to lower intraocular pressure, which can be done with eye drops, laser treatment, or surgery⁵

For more information about glaucoma, visit [FightingBlindness.ca](https://www.fightingblindness.ca).

1 "Glaucoma" – Canadian Ophthalmological Society: <https://www.cos-sco.ca/health/glaucoma/> and <https://www.cos-sco.ca/canadian-ophthalmological-society-puts-glaucoma-awareness-month-in-focus-through-photographic-works-of-toronto-based-photographer/>

2 "Glaucoma" – CNIB: <https://www.cnib.ca/en/sight-loss-infoyour-eyeseye-diseases/glaucoma?region=on#:~:text=More%20than%2025%2C000%20Canadians%20have.damage%20to%20the%20optic%20nerve.>

3 "Eye Exam Frequency Recommendations" – Canadian Ophthalmological Society: <https://www.cos-sco.ca/when-should-you-see-an-ophthalmologist/>

4 "Glaucoma" – CNIB: <https://www.cnib.ca/en/sight-loss-infoyour-eyeseye-diseases/glaucoma?region=on#:~:text=More%20than%2025%2C000%20Canadians%20have.damage%20to%20the%20optic%20nerve.>

5 "Treatment of Glaucoma" – Glaucoma Research Society of Canada: <https://www.glaucomaresearch.ca/glaucoma-treatments/>

The Honourable Judy A. Sgro Introduces Bill C-284 to Establish a National Eye Care Strategy



The Honourable Judy A. Sgro, MP for Humber River – Black Creek, has long demonstrated an unwavering commitment to public service and has served in various capacities at both the federal and municipal levels of government for over 30 years. Recently, she had the opportunity to advance an important issue that's near and dear to her heart: vision health.

On June 14, 2022, Sgro introduced her Private Member's Bill, C-284, entitled "An Act to establish a national strategy for eye care," in recognition of the fact that Canadians' access to eye care varies widely from province to province, causing variable health outcomes and inequalities in our vision health system. The initiative is also in keeping with the World Health Organization's March 2022 launch of a guide on eye care, *Universal Health Coverage and Eye Care: Promoting Country Action*.

Sgro's bill, if passed, commits the government to a national strategy dedicated to improved access to eye care and rehabilitation services – a strategy that also envisions the creation of a Vision Desk at the Public Health Agency of Canada and investments in research to find new treatments to prevent and stop blindness.

The Canadian Council of the Blind sat down with Sgro to discuss the new bill, what prompted it, and its current status.

MPs don't often get a chance to table Private Member's Bills. How did this come about? Following every election, MPs' names are pulled in a random draw to establish the list for the consideration of Private

Members' Business. My name was pulled, making me eligible to table a Private Member's Bill, which is a bill that's introduced by an MP without party affiliation, calling for a specific legislation, without committing the government to any spending.

Why did you choose to focus your bill on vision health? This is a personal issue for me. Throughout my 33 years in political office, I had a mentor, and he had age-related macular degeneration (AMD) when he died two years ago. My grandmother was blind, as is my aunt. I'm doing this for them.

We take our vision for granted. From social isolation to depression to travel difficulties, there are so many challenges when one can't see. Many people never stop to consider what it would be like to go blind. We have to increase awareness of vision loss and of what we should be doing every day to protect our eyesight.

What's the present status of the bill, and do you expect it to pass? By the time this magazine comes out, the bill will have undergone its first hour of debate. It'll undergo a second hour, then it goes to committee, and then it goes back to the House of Commons for a vote. If that's positive, it'll get sent on to the Senate. We're moving it along as fast as we can and I'm optimistic that it'll be passed by the end of the year. So far, it appears to have unanimous support.

I'm thrilled to be in a position as an MP, on behalf of my family and all Canadians, to truly make a difference by putting forward this bill, which will open the door for more recognition of vision loss and its implications.

Bill C-284 will have a direct, positive impact on Canadians' vision health now and for generations to come. If you believe in prioritizing Canadians' vision health and eye care, [send an email to your Member of Parliament](#). With gratitude, the Honourable Judy A. Sgro, MP, and the Canadian Council of the Blind.

VIA Rail's 2022-2025 Accessibility Plan Charts the Course for a More Inclusive Travel Experience

CATHERINE LANGLOIS, SENIOR ADVISOR OF UNIVERSAL ACCESSIBILITY, VIA RAIL

VIA Rail Canada (VIA Rail) is driven by its core value of going further together in every effort we're undertaking as part of our transformation into a vehicle for change in Canada.

Listening to and incorporating the various needs, expectations, and realities of our passengers has always been fundamental in our journey to becoming Canada's most accessible intercity mode of transportation.

Across Canada, 6.2 million people, or 22 percent of the population, identify as having a disability, and that number is expected to increase as the population ages. That's why VIA Rail is proud to be the first federal organization to table its 2022-25 Accessibility Plan under the Accessible Canada Act.

We understand the importance of listening to our passengers as we work toward offering barrier-free transport, which is why we consulted a wide range of advocacy groups as we developed this plan to make sure we were capturing the needs and expectations of the diverse Canadian population. Building on VIA Rail's universal accessibility plan, this multi-year plan aims to make accessibility a key component of every decision-making process.

Highlights of the 2022-2025 accessibility plan include:

- The creation of American Sign Language (ASL) and Langue des Signes Québécoise (LSQ) videos on VIA Rail's website
- Ongoing accessibility awareness training for all our employees, from on-train service, to customer care, to office employees and executives

- Improved equity in recruitment by removing bias in the hiring process and making our accessible hiring policy more visible to job seekers
- An accessible procurement process to incorporate accessibility early on in decision-making before projects are launched

VIA Rail teams have been working to improve accessibility for years ahead of this plan. Whether it's the new corridor fleet, which will deliver an unparalleled, barrier-free, and fully accessible travel experience, on-board announcements, or accessibility improvements to the Ottawa station, we've already taken important actions and will continue to ensure that we work to create an environment in which all people can travel autonomously and confidently.

In addition to seeking input on this plan, VIA Rail has performed tests on its new fleet of train in Ottawa with people with disabilities. Those tests were done to ensure all accessibility features onboard were ready to meet the needs of clients with disabilities. VIA Rail is also launching its new reservation system that will now allow clients with specific needs to book their tickets autonomously.

VIA Rail is committed to continually learning from our passengers, employees, and Universal Accessibility Advisory Committee to remove existing barriers, prioritize solutions, and become agents of transformation to foster a culture of respect, dignity, and inclusion. Through this plan, we're doing exactly that because we believe that it's time to create a barrier-free travel experience for every passenger, from reservation to destination.

A Report Card on Vision Health in Canada 2021—The Impact of the COVID-19 Pandemic



DR. KEITH GORDON, SENIOR RESEARCH OFFICER, CANADIAN COUNCIL OF THE BLIND
PHOTO BY: **ANDRE MARTIN**

In late 2022, the Canadian Council of the Blind, in collaboration with Fighting Blindness Canada, conducted a follow-up study to the Cost of Vision Loss and Blindness in Canada 2019 report. This follow-up report card reviewed the current state of vision health in Canada in 2021 by combining quantitative data from various Canadian sources with quantitative and qualitative data from a new survey of Canadians living with vision loss (VL), conducted in July 2022. In addition, interviews were conducted with ophthalmologists, optometrists, and vision stakeholder organizations to determine whether the quantitative data was supported by their experience.

The report card found that the Canadian health care system continues to face challenges brought on by the pandemic. While the report did show some progress in delivery of services, we are still facing a crisis when it comes to surgical backlogs and growing wait times to access critical eye care.

Eye surgery was dramatically impacted by the pandemic. While there was an increase in the number of eye surgeries performed in 2021 compared with 2020, there were a total of 108,000 fewer ophthalmic surgeries performed in Canada in 2021, compared with 2019. While wait times for surgery had decreased in 2021, they had still not reached pre-pandemic levels. Despite commitments from federal and provincial governments to increase funding to address the surgical backlog, staff shortages remain a critical issue impacting the delivery of Canadian vision health care.

Maintenance of one's eye health requires regular eye examinations. In the first year of the pandemic, we reported that 2.9 million fewer visits were made to optometrists in 2020 compared to 2019. The report card showed an improvement in the number of eye examinations compared with 2020 but that the number had not yet reached pre-pandemic levels, showing a decrease of 1.8 million eye examinations in 2021 compared with 2019. Two thirds of Canadians had not had an eye examination in the previous year. Eye doctors interviewed for the report card study said that they had patients coming to their clinics with irreversible VL after protracted periods of not receiving eye care.

The report card estimated the total cost of vision-related research in 2021 at \$21.3 million, essentially unchanged from 2019.

The report card study included an extensive survey of 572 Canadians living with VL to obtain an update as to what impact the COVID-19 pandemic had had on the VL community. The survey, conducted in July 2022, was similar to that conducted in April 2020, at the height of the pandemic. The survey found that the VL community was faring much better than they were in 2020. People were going out of their homes for necessary appointments and were participating in more activities. Concerns about issues such as social distancing had diminished, and the community was vaccinated at a level greater than the overall Canadian population in spite of no government having given them priority status with respect to vaccination. In general, the level of stress and anxiety felt by the community was much lower than that revealed in our 2020 report but there were still a significant number of people exhibiting high stress levels.

The report card assessed whether there had been any progress in achieving the three key recommendations of the Cost of VL in Canada report.

The first recommendation, that Canada create a National Vision Health Strategy to provide an integrated approach to improving vision health, has shown progress due to the tabling of Bill C-284 in the House of Commons on June 14, 2022, by the Honourable Judy A. Sgro, P.C., MP, calling on the government to develop a national eye care strategy. Bill C-284 will commit the government to a firm timetable of one year from the day of passage to produce a national strategy on how to support eye care and deal with VL. The second recommendation, that a vision health desk be created within the Public Health Agency of Canada, remains on hold pending the outcome of Bill C-284, and the third recommendation, arguing for an increase in funding for vision-related research, has shown little change in the past year.

In summary, the Report Card on Vision Health in Canada 2021 showed an overall improvement in the state of vision health compared with 2020, but there is still a great need for improvement and a national strategy for management of this improvement.

nAMD Barometer

Leading the way to improved patient care in nAMD

Approximately **250,000** Canadians have vision loss due to neovascular age-related macular degeneration (nAMD)¹, also known as wet age-related macular degeneration (wAMD). Regular treatment can stabilize disease, leading to visual gains that can be maintained with continuing treatment. However, up to **50%** of patients with nAMD globally stop treatment by **24 months**, and up to **42%** of patients stop treatment because they think that treatment is **not helpful** or **not required**².

The nAMD Barometer Leadership Coalition is an international group of experts in the field of retinal disease, vision care and aging, convened to develop evidence-based solutions for optimal management of nAMD, with the aim of improving patient adherence and persistence to treatments.



The Leadership Coalition is conducting a series of evidence-generation initiatives to help understand why non-adherence and non-persistence to some ongoing treatments for nAMD therapy occurs, which will help design interventions to support changes in behaviour and optimize treatment:

- Systematic literature review to identify risk factors associated with non-adherence and non-persistence – *recently published in Ophthalmology*²
- Standardization of definitions of 'non-adherence' and 'non-persistence' to enable consistency and alignment in future data collection – *recently published in JAMA Ophthalmology*³
- In-depth semi-structured interviews with patients to identify modifiable and non-modifiable risk factors to increased patient (non-) adherence and persistence
- Multi-country, comprehensive, market research survey of patients, healthcare professionals and allied health staff to quantify trends and perspectives, cultural differences, and healthcare systems

The efforts of the nAMD Barometer Leadership Coalition aim to uncover meaningful and practical interventions to inform future practice and policy, with the collective goal of improving the lives and livelihoods of patients.

References:

1. Fighting Blindness Canada. <https://www.fightingblindness.ca/eyehealth/eye-diseases/age-related-macular-degeneration/>. Accessed April 12, 2023
2. Okada M, et al. *Ophthalmology*. 2021;128:234–247;
3. Okada M, et al. *JAMA Ophthalmol*. 2021 online.



Ensuring Ontarians Have Access to High-Quality, Publicly-Funded Eye Care

THE HONOURABLE SYLVIA JONES, ONTARIO'S DEPUTY PREMIER & MINISTER OF HEALTH

We all recognize that access to publicly-funded health care is a fundamental part of being Canadian. That includes having access to the right care, at the right time, and in the right place, including to protect and maintain our eyesight.

As Ontario's Deputy Premier and Minister of Health, I'm proud of the important progress made in the last several months to ensure people have access to high-quality, publicly-funded eye care.

The way eye care is delivered has changed over the years. It's important to work with Ontario's eye care professionals, who play a key role in our public health care system, on a path forward to ensure care is there for those who need it.

On March 21, we reached a historic and sustainable agreement with the Ontario Association of Optometrists (OAO). Through their OHIP card, people of all ages will continue to be connected to high-quality and publicly-funded eye care that better reflects the latest best practices and expert advice.

This agreement demonstrates a positive and productive relationship built on open dialogue, mutual trust, and a shared commitment to connect Ontarians with the most suitable eye care, where and when they need it.

Eye diseases affect a significant proportion of the population and can have a profound impact on a

person's quality of life. Therefore, it's vital to invest in the research and development of innovative treatments that can provide better outcomes for patients.

That is why earlier this year, we were proud to announce an investment of \$2.9 million in Luxturna® to establish a provincial gene therapy program that will target blindness for those suffering from a debilitating genetic eye disease called inherited retinal disease.

Luxturna® is the first Health Canada-approved gene therapy for this disease and its historic approval is one the vision community had been waiting on for decades. Prior to its approval, there was no effective treatment available for those living with this inherited vision loss. Thanks to this new therapy, individuals living with this rare disease will have access to a life-changing treatment that will provide them with the potential for greater independence for themselves and their families.

We're forging ahead on our plan to connect more Ontarians to convenient health care closer to home. This means working together with all our partners as the field of eye care grows and changes to ensure optometrists and other eye care professionals can continue providing the high-quality access to care that patients deserve, both now and for future generations.



Canadian Council of the Blind

Local CCB Chapters

BC-YUKON DIVISION

100 Mile House & District Chapter
Alberni Valley Chapter
All Abilities Chapter
Campbell River White Cane Chapter
Camp Bowen Society for the Visually Impaired Chapter
Chilliwack & District Chapter
Comox Valley Chapter
Dogwood Chapter
Festival of Friends
GTT BC Chapter
Kamloops White Cane Chapter
Kelowna Blind Curlers Chapter
Knotty Knitters & Crazy Crocheters
Low Vision Group Qualicum Chapter
Lower Mainland Chapter
PoCo VIP Chapter
Powell River White Cane Chapter
Prince George Chapter
Prince George Curling Chapter
Provincial Book Club
South Okanagan Chapter
Sunshine Coast White Cane Chapter

Vancouver Arts & Culture Lovers Chapter
VIBE Creston Chapter
West Kootenay Chapter

ALBERTA DIVISION

Calgary Chapter
Edmonton Cribbage Chapter
GTT Edmonton Chapter

SASKATCHEWAN DIVISION

Moose Jaw White Cane Club
Regina White Cane Club

ONTARIO DIVISION

Adventures Chapter
Afloat Chapter
Chatham-Kent Chapter
Club '60' Barrie Chapter
Cornwall Chapter
Dragon Boat Toronto Chapter
GTT North Bay Chapter
Hamilton Blind Curlers Chapter
Hamilton Chapter
Hamilton Juniors Chapter
Hands of Fire Chapter
Kawartha Chapter
Kingston Friendship Chapter

Limitless Chapter
Listeners Book Club
London Chapter
London Vision Impaired Curling Chapter
Mississauga V.I.P. Chapter
Ontario Visually Impaired Golfers Chapter
Ottawa Blind Curlers Club
Ottawa Chapter
Pembroke White Cane Chapter
Peterborough Chapter
Road Runners Chapter
Rocks Chapter
Thunder Bay & District Chapter
Toronto Blind Curling Club
Toronto Ski Hawks Ski Club Chapter
Toronto Visionaries Chapter
Waterloo Regional Club
Windsor/Essex Low Vision Social & Support Chapter
York Region Lighthouse Chapter

PRINCE EDWARD ISLAND DIVISION

Prince County Chapter
Queensland Chapter
Summerside Socialites Chapter

NEW BRUNSWICK DIVISION

Bathurst Club
Fredericton Club
Miramichi Club
Moncton Club
Saint John Club

NOVA SCOTIA DIVISION

Blind Sports Nova
Scotia Chapter
Crafts & Hobbies Chapter
Faith, Hope & Love Chapter
Sydney Chapter
Sydney Curling Chapter

NEWFOUNDLAND AND LABRADOR DIVISION

E.A. Baker Club
Helen Keller Club
Humber Valley Bay
of Islands Chapter

NATIONAL CHAPTERS

Blind Golf Canada Chapter

BOARD OF DIRECTORS

Jim Tokos (ON)
National President

Leo Bissonnette (QC)
1st Vice-President

Mike Vrooman (ON)
2nd Vice-President

Surander Singh (BC)
3rd Vice-President

Louise Gillis (NS)
Past President

Shane Cashin

Heather Annett

Christina Lewis

Charles Mossop

Sandra Poirier

Leslie Yee

STAFF

Jim Prowse – Executive Director

Nancy Yang – Accountant

Mohamed Selim – IT

Maria Jimena Flórea –
Office Administrator

Shelley Ann Morris –
Receptionist/Administration

Monica Reategui – Mobile Eye
Clinic Program Co-Coordinator

Corry Stuive – GTT West

Gerry Chevalier – GTT Edmonton

Ian White – GTT Toronto

Jason Fayre – GTT Toronto

David Greene – GTT Ottawa

Kim Kilpatrick – GTT Ottawa

**For more information about the CCB or to reach a National Board
or staff member, please contact us at our national office:**

Canadian Council of the Blind

14 Chamberlain Avenue, Suite 200, Ottawa, ON K1S 1V9

Tel: 613-567-0311
Toll-free: 877-304-0968
Fax: 613-567-2728

Email: ccb@ccbnational.net
Website: www.ccbnational.net

A national strategy to support eye health in Canada

98%

Canadians who say good vision health is critical/important to overall health

1.2
MILLION

Canadians living with vision loss

8+
MILLION

Canadians at risk of eye threatening conditions

\$32.9B

Annual cost of vision loss

The good news: vision loss can be prevented or treated in 75% of cases.

Making eye health, vision care and rehabilitation services a population health priority requires a national strategy for eyecare.

KEY GOALS OF BILL C-284:



Creation of a Vision Health Desk at the Public Health Agency of Canada



Increased research funding



Streamlining approval process for new medicines and technology to treat and prevent vision loss



Enhanced access to care for vulnerable populations, including Indigenous peoples, children and seniors



Funding for advocacy and support groups

Save our sight. Make vision health a priority for all Canadians.



CANADIAN ASSOCIATION OF OPTOMETRISTS
ASSOCIATION CANADIENNE DES OPTOMÉTRISTES



Canadian Ophthalmological Society
Société canadienne d'ophtalmologie
EYE PHYSICIANS | MÉDECINS ET CHIRURGIENS
AND SURGEONS | OPHTHALMOLOGISTES
OF CANADA | DU CANADA



CAOT - ACE
Canadian Association of Occupational Therapists
Association canadienne des ergothérapeutes



FIGHTING BLINDNESS CANADA
VAINCRE LA CÉCITÉ CANADA





Fighting Blindness Canada-Funded Research Develops New Therapy for Age-Related Macular Degeneration and Diabetic Retinopathy

SPECIAL TO WHITE CANE MAGAZINE / FIGHTING BLINDNESS CANADA

Fighting Blindness Canada (FBC) is the largest charitable funder of vision research in Canada, contributing critical funding for the development of sight-saving treatments for blinding eye diseases. By raising and stewarding funds, the organization is helping drive forward research that supports understanding why vision loss occurs, how it can be slowed, and how sight can be restored.

Today, FBC has invested in more vision research than ever before. In 2022, for example, the organization awarded \$2.6 million to 35 projects, enabling research into stem cell therapy, optogenetics, new drug therapies, and more. One of these funded researchers is Dr. Sachdev Sidhu from the University of Toronto, a biomedical engineer with extensive experience in drug development.

About Dr. Sidhu's research

Dr. Sidhu established the Toronto Recombinant Antibody Centre (TRAC), which houses a state-of-the-art platform to generate therapeutic antibodies for a spectrum of diseases, including cancer and infectious diseases. In 2022, Dr. Sidhu was awarded a research grant from FBC to extend this work to age-related macular degeneration (AMD) and diabetic retinopathy (DR). This project is testing whether an antibody therapy can heal damage to the blood-retinal barrier caused by AMD and DR.

About the blood-retinal barrier

An intact blood-retinal barrier is important for proper retinal function but is disrupted in many eye diseases, including wet AMD and DR. In these diseases, uncontrolled blood vessel growth disrupts the barrier, allowing fluid to leak into the eye. If untreated, this can lead to retinal damage and vision loss. The main treatment for AMD and DR is a medication called anti-VEGF, which reduces blood vessel growth. However, anti-VEGF treatments do not fix damage to the blood-retinal barrier, leaving the eye susceptible to further damage. Dr. Sidhu has developed a new antibody treatment which has the potential to restore the blood-retinal barrier.

The future of developing antibody treatments

In the last 20 years, antibody drugs have taken centre stage as effective treatments for many diseases, including cancer. Antibodies are normally produced by the immune system to fight infection. They work by identifying and binding foreign objects such as bacteria or viruses. Thanks to advanced technology, it is now possible to engineer antibodies in the laboratory that recognize and bind specific molecules in the human body. These antibody drugs can stimulate or block biological processes such as cell growth or tissue repair.

Dr. Sidhu's team is currently conducting preclinical experiments to determine whether the new antibody treatment improves the integrity of the blood-retinal barrier in animal models of AMD and DR. The team will also examine how effective the antibody therapy is compared to the standard of care anti-VEGF treatment. The aim of the project is to gather enough data to enable the launch of a clinical trial to test this potential new treatment in humans.

"We're grateful to FBC and their donors for sponsoring this grant, which will greatly accelerate the development of our candidate drug so that it can be validated in experimental systems before moving on to clinical trials," said Dr. Sidhu.

FBC is excited to share about this project and its future findings with the vision loss community. Advancing critical sight-saving research is the organization's mission. Work carried out by FBC-funded researchers, like Dr. Sidhu's team, brings new innovative treatments and therapies one step closer to patients who need them most, reducing the risk of vision loss or blindness.

To learn more about FBC and to access eye health information research, visit www.fightingblindness.ca and follow the organization on Facebook @[fightingblindnesscanada](https://www.facebook.com/fightingblindnesscanada), on Twitter @[FB_Canada](https://twitter.com/FB_Canada), on Instagram @[fightingblindnessca](https://www.instagram.com/fightingblindnessca), and on YouTube @[FBFCanada](https://www.youtube.com/FBFCanada).

AMI Outlines Its Plans for an Exciting Summer of Content



With summer approaching, AMI has lined up an exciting programming schedule. From returning favourites and debuts on AMI-tv to informative and entertaining podcast content on AMI-audio, AMI furthers its vision to establish and support a voice for Canadians with disabilities, representing their interests, concerns, and values through accessible media, reflection, and portrayal.

May

***Disrupt* debuts Tuesday, May 2, at 8:30 p.m. Eastern on AMI-tv**

Fast-paced, experimental, and accessible, *Disrupt* showcases music, short films, poetry, animation, spoken word, comedy, dance, puppetry, and other mediums, with a disability-first punk rock attitude. Produced by Rachel Bower Productions, *Disrupt* features members of the disability community working behind the scenes as well.

***Fashion Dis* returns Wednesday, May 3, at 8:30 p.m. Eastern on AMI-tv**

Hosted by Ardra Shephard, Season 2 of *Fashion Dis* celebrates the head-to-toe overhaul of a frustrated style seeker discouraged by an industry that lacks adaptive options.



The cast of *Womb Envy*

***Womb Envy* debuts Wednesday, May 10, on AMI.ca and the AMI-tv App**

Created by Toronto drag artist Champagna, the web series *Womb Envy* is a story of second chances and inclusion. When a gay party boy's estranged small-town best friend shows up expecting him to play baby daddy, even a lover who is partially-sighted and an imaginary drag queen can't stop his womb envy.

***Mind Your Own Business* returns Tuesday, May 30, at 8:30 p.m. Eastern on AMI-tv**

Hosted by entrepreneur Kevin Shaw, who is blind, each episode features entrepreneurs in the disability community who aim to take their businesses to the next level with some help from high-profile Canadian mentors.

June

***By Hook or By Cook* returns Wednesday, June 14 at 8 p.m. Eastern on AMI-tv**

Bruce Cook, a stunt motocross rider who is disabled, wants to help others with disabilities enjoy life's possibilities with unique innovations that he and his friend, Christian, create. In Season 3, Bruce and Christian have spent many years facilitating adrenaline adventures for others. Whether racing on top of mountains or bungee jumping off the highest bridge in British Columbia, they know no fear and no boundaries. What will happen when two people whose passion lies in helping others get an opportunity to do something remarkable for themselves?

***Our Community* returns Thursday, June 15 at 8 p.m. Eastern on AMI-tv**

An all-new season of *Our Community* once again highlights the people, places, organizations, or things that have made life more enjoyable for Canadians living with a disability. Upcoming episodes follow young adults who are partially-sighted as they participate in a fashion show, Canada's first medical daycare for children, and the Capital City Condors, a hockey team that Canadians of all abilities can play on.

July

***Blind Adventures with Ron Walsh* returns Monday, July 17, at 8 p.m. Eastern on AMI-tv**

Join outdoors enthusiast Ron Walsh, who is blind, as he and his friends explore Saskatchewan and all of the exciting locations the province has to offer.



***Postcards From...* host Therese Estacion, who has limb difference, sits on an adaptive bike**

***Guide Dogs* debuts Tuesday, July 25, at 8 p.m. Eastern on AMI-tv**

Guide Dogs (working title) tells the story of the CNIB Guide Dog program. From being raised on a farm in rural Manitoba to training in Carleton Place near Ottawa, a guide dog's journey is quite an adventure!

***Adaptable Animals* returns Tuesday, July 25, at 8:30 p.m. Eastern on AMI-tv**

Adaptable Animals looks at the world of animals with disabilities, and the advances in veterinary medicine that provide them with prosthetics, thanks to the specialized work of Janice Olynich.

***Postcards From...* returns Thursday, July 27, at 8 p.m. Eastern on AMI-tv**

New host, new adventures! Join Therese Estacion, poet and member of the disability community, as she embarks on a multisensory journey, revealing a secret side to Canada we taste, touch, smell, see, and hear for the first time.

And don't forget AMI's two live daily shows! Join Dave Brown on *NOW with Dave Brown*, weekdays at 9 a.m. ET on AMI-tv, as he discusses the latest news, entertainment, sports, and current events through a disability lens. Then tune in to *Kelly and Ramya*, weekdays at 2 p.m. Eastern on AMI-tv and AMI-audio, for interviews and discussions about arts, entertainment, and the lifestyle issues that matter to you. Both *NOW with Dave Brown* and *Kelly and Ramya* are available as podcasts from your favourite podcasting platform.

Dates and times are subject to change. Please check [AMI.ca](https://ami.ca) or sign up for the AMI newsletter for the most up-to-date information.

[AMI.ca](https://ami.ca) is getting an upgrade! Coming this summer, the renamed, revamped, and free AMI+ will boast AMI original series and documentaries in a fresh, new layout. As always, AMI+ will feature customizable accessibility preferences for the blind and partially-sighted community we serve.

Over on AMI-audio, AMI is pleased to offer the following as video podcasts on YouTube.

Tripping On Air

Fashion Dis host Ardra Shephard, along with Alex Hajjar, brings her confessional/informational blog, *Tripping On Air*, to the podcast airwaves where she spills the tea on what it's really like to live with MS. Every month, *Tripping On Air* invites the cool kids of chronic illness to tune in, hang out, have a laugh, learn some tips, and, above all, feel seen.

Raising Kindness with Becki Zerr

In *Raising Kindness with Becki Zerr*, Becki and her son, Bennett, perform acts of kindness in such settings as shelters, community centres, and nursing homes in southern Saskatchewan. Along the way, listeners and viewers learn about the work being done at those venues and meet people who improve the lives of those in need.

The Blind Golf Canada Podcast

Hosted by Gerry Nelson and Darren Douma, *The Blind Golf Canada Podcast* champions the evolution of the AMI-supported sport, including its recent partnership with ParaGolf Canada. Summer episodes of *The Blind Golf Canada Podcast* feature highlights of the four ParaGolf Canada major events held every year.

Shaun of the Shed

Hosted by *Double Tap's* Shaun Preece from his shed in Manchester, *Shaun of the Shed* gives those new to the world



Shaun of the Shed host Shaun Preece smiles into the camera

of technology a helping hand with everything from using a screen reader or smart speakers to unboxing and starting up a new computer.

The Pulse

Host Joeita Gupta leads an in-depth discussion on issues impacting the disability community across Canada.

Low Vision Moments

Part story time, part comedy, part awareness-driven, *Low Vision Moments* with Jennie Bovard presents funny experiences that happen when you are blind or partially-sighted.

Don't miss audio-only podcasts *Kitchen Confession*, *Best of the Buzz*, *Accessing Art with Amy*, *Into You*, *AMI Audiobook Review*, *Connecting Disability*, *My Life in Books with Red Széll*, *Tales from the Halifax School for the Blind*, *Eyes on Your Money with Ryan and Becky*, *The Blind Reality*, and *Triple Vision*.

You can watch all of your favourite AMI-tv programs on our broadcast channels, on our website, AMI.ca, or by downloading the free AMI-tv App for Apple and Android devices.

AMI-audio programming and podcasts are available for download via your favourite podcasting app.

Keep up to date on everything going on at AMI and in the community we serve by signing up for the AMI Newsletter at AMI.ca/newsletter and have it delivered straight to your Inbox.

Want to have input into the future of programming at AMI? Join our Research Panel at AMI.ca/researchpanel.

Have you got an idea for an original television show or digital content you think is a good fit for AMI, or do you have a proposal for an episode or segment on one of AMI's existing shows? Pitch us at AMI.ca/independent-producers.

AMI-audio, AMI-tv, and AMI-télé are all available as part of basic digital packages offered by most television providers across the country. If you have basic cable, you have access to AMI.

Visit AMI.ca, AMItel.ca, or email info@ami.ca to learn more about AMI. Follow AMI on Facebook ([@AccessibleMediaInc](https://www.facebook.com/AccessibleMediaInc)), Twitter ([@AccessibleMedia](https://twitter.com/AccessibleMedia)), and Instagram ([@accessiblemediainc](https://www.instagram.com/accessiblemediainc)).



Shaping the future of vision.

At Roche, we are passionate about saving people's eyesight from the leading causes of vision loss. Our experienced teams are working to discover and develop innovative solutions, aiming to redefine standards of care for people living with some of the leading causes of vision loss.

www.rochecanada.com

If you require this information in an accessible format, please contact Roche at 1-800-561-1759.

© 2023 Hoffmann-La Roche Limited



Hoffmann-La Roche Limited
Mississauga, ON L5N 5M8



Seeing the World Before Their Vision Falters

PHOTOS BY: EDITH LEMAY

A Canadian family is on a yearlong journey across Asia and Africa because three of their four children have an eye condition that causes blindness.

MIKE IVES

For their youngest son's fifth birthday this summer, Edith Lemay and her husband took their children on a hot-air balloon ride above central Turkey that began before dawn.

As the sun rose over the Cappadocia region, it revealed other balloons floating in the sky and some chimney-like rock formations on the ground below – a transcendent experience that her 9-year-old likened to a dream. “That’s what we all felt because it was way too magical,” Ms. Lemay said.

Six months ago, Ms. Lemay, 44, and her husband, Sebastien Pelletier, 45, left their home in the Montreal area for a yearlong trip across Asia and Africa. Three of the French Canadian couple’s four children have a rare eye condition that has already impaired their vision and will slowly destroy it entirely unless an effective treatment materializes. The trip is a chance for them to see memorable sites while they still can.

In another sense, Ms. Lemay said, her family’s journey across Asia and Africa is a catalyst for her three children with retinitis pigmentosa – Laurent, 5, Colin, 7, and Mia, 11 – to develop what she called “solution-oriented” behaviour in the face of setbacks large and small, a habit that could prove useful as their eyesight continues to diminish. (Her oldest boy, Leo, 9, does not have the condition.)

Ms. Lemay said she also hoped the trip would force her children to appreciate how lucky they are in a world where many of their peers do not have electricity in their homes, books in their schools, or other comforts that people in wealthy countries take for granted.

“I want them to look at their life and see what’s good, what’s beautiful in it,” she said by phone last month from Indonesia, as Laurent splashed in a nearby swimming pool. “Not the little problem with their eyes.”



Playing soccer with local boys in Zanzibar.



Mia Pelletier, 11, on a hot-air balloon ride in central Turkey in July.



Meeting an eagle hunter near Ulan Bator, the capital of Mongolia.

The prognosis

Retinitis pigmentosa encompasses a group of hereditary disorders that affect an estimated one in 3,000 to 4,000 people worldwide, including as many as 110,000 in the United States, according to the National Organization for Rare Disorders, a non-profit in Massachusetts. It causes slow degradation of the retina, and the symptoms can develop over decades.

People with retinitis pigmentosa typically begin to lose their vision during childhood. In the next phase of the disease's progression, they start to lose their peripheral vision, making it hard for some children to play sports or to avoid bumping into their classmates in the hallways, said Alfred S. Lewin, a professor emeritus of molecular genetics and microbiology at the University of Florida in Gainesville.

In advanced stages of the condition, their vision becomes so impaired that they are considered legally blind, though most do not completely lose their ability to detect light, Dr. Lewin said. But several promising new experimental therapies are in human clinical trials and could be approved in the next few years, potentially helping many children and young adults with the condition avoid blindness, he added.

For now, existing therapies can help slow the progression of the condition, said Lin Bin, a professor of optometry at Hong Kong Polytechnic University.

"These treatments can buy time for the patients for new research breakthroughs and new and more effective treatments," he said.

Facing reality

Ms. Lemay said that while she and her husband were cautiously hoping for a breakthrough treatment, they did not want to set themselves or their children up for disappointment.

"If a new treatment comes, good, we'll be super happy," she said in mid-September from the Gili Islands of Indonesia, where her children had just snorkeled with turtles. "But we're not going to be sitting there waiting on a cure. We want our children to accept their situation and learn how to make the best of it."

At this early stage, the children do not talk much about their eyesight, and they occasionally even crack jokes about their condition, Ms. Lemay said. The only reason she has been discussing it so much lately is because reporters keep calling to ask about the round-the-world trip.

"It's not something sad in our family," she said. "It's just something that's going to happen, and we're going to face it."

At the same time, she said, it can be hard to discuss retinitis pigmentosa with her children, especially Laurent, who doesn't yet understand its full implications. "How am I going to cross the street?" he asked her this summer as the family drove through the Mongolian Steppes in a Russian-built van. "Will my wife be blind?"

Another time in Mongolia, Ms. Lemay was gazing at the Gobi Desert's night sky when she remembered that her three children who have the condition cannot see stars because of their night-vision loss. She did not bother to wake them up.



Edith Lemay, right, and her family in Namibia in April.
From left: Laurent, Sebastien, Colin, Leo and Mia Pelletier.



Swimming in a cave in Zanzibar.



Mia, 11, looking at a rainbow from the roof of the family van in Mongolia.

Seeing the sites

Ms. Lemay said that the trip so far had been loaded with adventure and serendipity, and that her children never seemed to become bored.

Their journey began with a three-month, coast-to-coast, overland trip across southern Africa. An early highlight for the children, she said, was a 24-hour train ride across Tanzania, where they slept in bunk beds and watched in awe as vendors approached the windows to hawk bananas.

After a month in Turkey, the family travelled to Mongolia and spent more than a month on a road trip through the countryside, staying in yurts and eating boiled mutton.

The children loved that, too, even if the toilet facilities along the way ranged from “abominable to bearable,” as Ms. Lemay put it on her Facebook page. Her daughter, Mia, enjoyed riding horses so much that she cried tears of joy. And even though Mia and two of her brothers can no longer see stars, they enjoyed looking at pictures of the Gobi’s night sky on their mother’s laptop.

Soyolsaikhan Baljinnyum, the family’s tour guide in Mongolia, said by phone that the family was one of the kindest he had ever met.

“It really hurts me when I think about them losing their vision,” he said of the three children with the eye condition. “But there’s always hope; there could be a miracle.”

Ms. Lemay, who works in health care logistics, said her family planned to spend the next two months island-hopping across Indonesia by boat and bus. From there, they intend to visit Malaysian Borneo, Thailand, Cambodia, and Vietnam, with a potential stop in Hawaii on their way back to Canada. But it’s all subject to change: Their itinerary is fixed only about a month in advance.

Among the surprises so far, Ms. Lemay said, is the way her children tend to fixate on things that seem peripheral to whatever their parents had planned to show them, such as stray cats and dogs, or a tiny beetle they spotted at the base of a colossal red sand dune in Namibia.

“Hey, we came all the way around the world to see that, and you’re looking at a little bug?” Ms. Lemay said she asked them at the UNESCO World Heritage site.

“But if we listen to them,” she added, “they show us that there is beauty everywhere.”

Revisiting Pre-COVID Perspectives on Vision Loss: What Has Changed?



CHAD ANDREWS, RESEARCHER & CONSULTANT

Early in 2020, before the magnitude of COVID was truly felt or known, Canada's largest blindness organizations released a series of white papers marking the occasion of 20/20, a symbolic year for the vision loss (VL) community. Over 300 VL stakeholders were surveyed and interviewed for those papers, lending their insights to topics ranging from employment and isolation to eye exams and gene therapy.

Much has happened in the three years since the papers were published; the COVID-19 pandemic, more specifically, with its shifts in culture, work, economics, technology – the list goes on. For those connected to the 20/20 papers, the question is impossible to ignore: what has changed?

Like anything related to the pandemic, the question is complex. First, a comprehensive update of those papers, one that would allow us to compare pre-COVID to “post,” has yet to be undertaken. Nevertheless, it is worth revisiting – however casually – those earlier perspectives in light of what we know now.

As most patient groups are aware, the pandemic exposed the precarious nature of our access to essential health care. Before COVID, the community made it clear that far too many Canadians struggle to access treatments, including those for glaucoma, diabetic retinopathy,

age-related macular degeneration, and more. They also articulated transportation as a barrier, particularly in Canada's rural and remote regions. COVID did not improve this situation. According to last year's Report Card on Vision Health, access to medicine and treatments was a primary concern for the VL community, with many reporting an increase in VL resulting from an inability to access treatments or see an eye doctor. Unfortunately, this issue will likely persist for some time as our country addresses a large backlog in vision health services.

Employment continues to be a central concern as well. Before COVID, it was already the case that too many members of the community were under or unemployed, often because of the added barriers they face when seeking and maintaining meaningful employment. We do not have current statistics on the VL workforce, but it is safe to assume that while some barriers may have lessened – the ubiquity of Zoom may have diminished the burden of transportation, for instance – others have persisted or intensified. Perhaps most crucially, COVID has likely done very little to address the biases and prejudices faced by those with VL in the context of work, and the increased reliance on technology to facilitate remote work has probably amplified the already-apparent lack of access to truly

accessible devices. According to the Report Card, employers are not adequately funding the accessible technology that people require to work effectively at home. Given the fact that remote work is here to stay, this obviously needs to be addressed.

For many, isolation and loneliness were part of the daily reality of VL pre-COVID. Today, they continue to be enduring and multi-faceted issues. As with work, the remote tech boom has surely helped in some cases, but we also know that experiences of isolation, loneliness, and seclusion were felt more deeply by some as a result of COVID-related lockdowns, reduced access to social programs, the generalized lack of “feeling safe,” and more. The Report Card has shown that these issues have improved somewhat since the early days of COVID (see Dr. Keith Gordon's article), but we need to continue to study the problem and support those who suffer in silence.

There is still much that we do not know regarding the impact of COVID on those with VL. As the white papers did three years ago, it is essential that we maintain a dialogue with patients, policymakers, scientists, elected officials, and others to develop a clearer picture of VL in Canada, and to collectively plot our way toward a better future for the community.

Glaucoma Care in Canada: National Survey

Glaucoma is an eye disease where increased eye pressure can damage the optic nerve. Glaucoma impacts over 728,000 Canadians and is one of the leading causes of blindness in Canada.¹


A SURVEY OF 150 CANADIANS WITH GLAUCOMA REVEALS:

The average age of
GLAUCOMA DIAGNOSIS is **51**

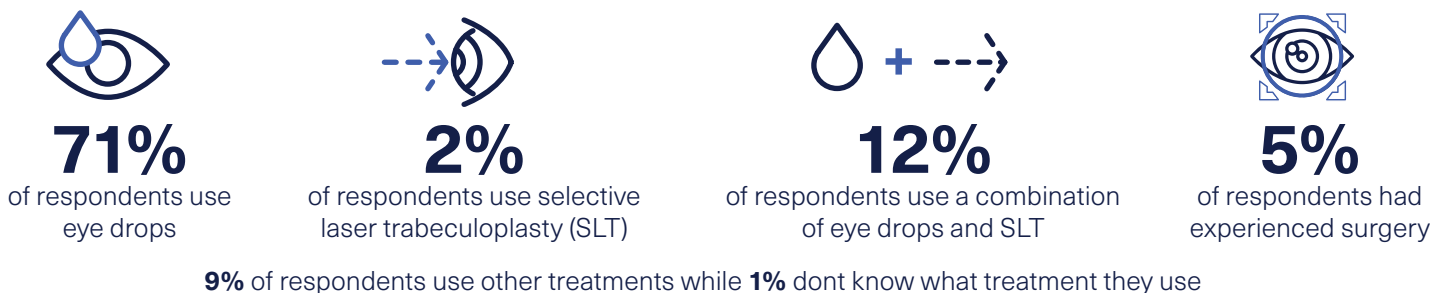
QUEBECERS ARE MORE LIKELY
to be diagnosed between ages
26-41 & 42-57, and **LESS LIKELY** at age **65+**



Nearly
7 IN 10
GLAUCOMA PATIENTS
don't know what type of glaucoma they have


 **22%** of glaucoma patients experienced some **VISION LOSS** before being diagnosed


Current therapeutic treatments used for glaucoma:





Accessing resources and information on glaucoma:



 **87%** of glaucoma patients are aware that you can **lose vision if daily eye drops are not taken** as recommended for glaucoma

 **1/2** of patients strongly disagree that you can **regain vision loss** due to glaucoma

 **59%** of patients say **at least one of their family members has also been examined** to check if they have glaucoma

 **55%** of patients had **some knowledge** of glaucoma prior to diagnosis
45% of patients had **no prior knowledge**

Survey Methodology:

Leger Research online survey of 150 Canadians who have been diagnosed with glaucoma between February 24-26, 2022. The estimated margin of error is ±8.0%, 19 times out of 20.

References:

1. Fighting Blindness Canada. About Glaucoma. Retrieved from <https://www.fightingblindness.ca/eyehealth/eye-diseases/glaucoma>. Accessed March 2022.

© 2022 AbbVie. All rights reserved.
CA-OPHTHG-220008A

abbvie

MEMBER OF
INNOVATIVE MEDICINES CANADA

The Halifax Vision Loss Rehabilitation Clinic Offers Integrated Services for Greater Patient Care

CAITLYN CREWS

PHOTOS BY: VLRC PHOTO LIBRARY

When you're first diagnosed with an eye condition, things can often feel uncertain. You're trying to figure out what your diagnosis means not only for your health, but for your life. Now, a new integrated care clinic in Halifax, N.S., is offering a model for practitioners across the country, situating Vision Loss Rehabilitation Canada (VLRC)'s clinic into the same space as an ophthalmologist so that referrals are easy and care is immediate.

Rhiannon Verran is a Certified Orthoptist, Certified Low Vision Therapist, and Manager at the Marjorie Fountain Low Vision Clinic, which was initially opened in 2017 by VLRC in Nova Scotia. The clinic offers a one-of-a-kind experience that provides patients with low vision access to the services they need across the health care continuum.

"[It's] all about setting up a model where [our clients can benefit from] an ophthalmology visit with a comprehensive eye examination, and then still be able to get the low-vision piece from us," says Verran. Often the ophthalmologist, Dr. Anu Mishra, will recommend some supports during patient visits, with VLRC staff then providing their own expertise. It's a prime example of how integrated services offer a more holistic and inclusive approach to patient care.

Mairin Hogan, a Certified Orthoptist and Certified Low Vision Therapist at VLRC, is often the one talking patients through their visit, which she says begins

by adding a history of the patient's lifestyle to the ophthalmologist's medical questionnaire.

"We want to know not only their medical history but also their occupational history and their recreational history. It's really important to get into the nitty gritty because those are the things that low vision will impact on a day-to-day basis," says Hogan.

From screen readers to mobility training to braille services, Hogan and her colleagues are able to offer many options that the patient may not be aware of, and with samples available, they're able to train patients immediately. The space even has a display kitchen so staff can show patients how they can apply low-vision labelling to their microwave or stove. Patients attend the clinic for a wide range of vision needs and come from all over the Maritime provinces, so the added advantage of a one-stop visit is clear.

Having all of these supports integrated helps to reassure the patient that there are both tools and experts available to help them live the lives they choose.

"Patients with low vision come to us very concerned, because they've gotten this diagnosis that they don't really understand," says Verran. "We take a lot of time during our assessments to give them that education piece, and we can give them hope. I always say, 'You've got a whole team behind you now. So, you don't have to feel alone – we're going to be able to help you with this.'"



A low-vision patient at the Halifax Vision Loss Rehabilitation Clinic gets support in using an assistive technology device.



Comprehensive eye examinations are part of the Halifax Vision Loss Rehabilitation Clinic's integrated service offerings.



The Halifax Vision Loss Rehabilitation Clinic's display kitchen, where patients learn how to apply low-vision labelling.

LEADERS IN COMPLEMENT

at the forefront of
developing targeted

C3 therapies



Apellis

Want to Become a Podcaster? Learn the Ropes with Lawrence Gunther

Lawrence Gunther is the producer and host of two podcasts, *The Blue Fish Radio Show* and *Outdoors with Lawrence Gunther*. Having produced close to 500 episodes, Gunther has now released new training resources featuring his 10 years of experience for those interested in producing their own podcast.

Having been blind since the age of eight, Gunther has embraced the ancient arts of knowledge-keeping and storytelling. He's also a committed conservationist, outdoor writer, blogger, filmmaker, and TV personality. His Masters in Environmental Studies drew heavily on traditional and local knowledge, but what truly makes Gunther extraordinary is his capacity to visualize and give voice to the largely-silent underwater world. In 2012, Gunther founded the charity Blue Fish Canada to ensure that revenues generated by his award-winning documentary *What Lies Below*, featured on AMI-tv and CBC's Documentary Channel, are used to strengthen nature.

Working in collaboration with the River Institute, Gunther has developed a new educational program to encourage and support people interested in starting their own podcast. To order these free resource materials, visit <https://forms.office.com/r/tgLWYqF5qm>.



PHOTO BY: THEO EUTENEIER

For more info about Gunther and the podcast *Outdoors with Lawrence Gunther*, visit www.lawrencegunther.com.

To listen to Gunther's other podcast, *The Blue Fish Radio Show*, visit www.bluefishradio.com.

For more stories and tips about Gunther's outdoor adventures and time on the water, visit www.blindfishingboat.com or www.feelthebite.ca.



FIGHTING
BLINDNESS
CANADA

VAINCRE
LA CÉCITÉ
CANADA

FIGHTINGBLINDNESS.CA

Find your answers on eye diseases.
Trouvez vos réponses sur les maladies
des yeux.

@Fightingblindnesscanada



Halifax Transcriber Designs Canada's First-Ever Indigenous Braille Code

STEVE GOW

PHOTO BY: CHRISTINE MUISE

A Halifax woman is receiving widespread praise for her creation of a braille code specifically designed to help blind Indigenous persons.

Certified braille transcriber Christine Muise earned the Louis Award at this year's annual meeting of the American Printing House for the Blind in honour of the Mi'kmaw Braille Code she developed earlier this year.

"It's called the Louis Award, but the technical term for it is creative use of braille," notes Muise, who was surprised but thrilled by the recognition from the American-based non-profit organization aimed at promoting independent living for the visually-impaired.

"When the code got finalized in Canada, I sent them a copy of it [because I know] there is a large Mi'kmaw community in Maine, so just in case it came up, I wanted them to know this was available," says Muise about how her work got noticed. "The lady that I sent it to is actually the one who nominated me for it. I found out while I was down there and met her."

Also endorsed by Braille Literacy Canada, the nation's governing braille authority, Muise's Mi'kmaw Braille Code ensures that blind readers of Mi'kmaw now have a standardized, consistent braille code available to them – giving the underrepresented visually-impaired group something they never had previously – the ability to read.

"When I started looking into it, I found out there was no braille

for any Indigenous language in Canada and there was only one or two in the States," says Muise, adding she's a big advocate for the visually-impaired.

"I think braille should be available to anyone who wants or needs it," continues Muise. "The blind are already a pretty underserved population so you can imagine how underserved a Mi'kmaw blind population must be."

Muise came up with the idea to create an Indigenous braille code in April, shortly after thousands of unmarked graves began to be discovered at various residential schools around the country.

"It just kind of got me thinking about what someone like me could do to make any sort of difference," recalls the former Chronicle Herald graphic designer who now works with the Atlantic Provinces Special Education Authority (APSEA). "I figured there would probably be a resurgence of people wanting to regain their language, and I knew from the few times I had come across Mi'kmaw in local textbooks here that there wasn't anything, [so] I thought that was a way I could make a difference."

Through her dedication on the development of the Mi'kmaw Braille Code, she's definitely poised to change many lives.

Created in collaboration with native linguist Dr. Bernie Francis (who helped developed a new orthography of the Mi'kmaw language) in consultation with other experts, Muise's code has



Christine Muise received the Louis Award at the 2022 meeting of the American Printing House for the Blind.

been supported and approved by Dr. Francis and long-serving Chief of Membertou First Nation, Terry Paul.

"Creating a braille code that represents our language plays an important role in communication and accessibility to Mi'kmaw cultural education for future generations of Indigenous students," declared Paul in a statement.

Muise notes that with Nova Scotia officially passing the Mi'kmaw Language Act recognizing Mi'kmaw as the official first language of the province, she hopes her braille code will provide an additional way of helping to promote and revitalize the Indigenous language.

"That was the whole goal basically – to have it live somewhere where someone would actually find it," says Muise, adding that while she hasn't yet tackled any other Indigenous languages yet, she's not above taking calls.

"I'm not going to just go and tackle them all," laughs Muise. "[But] I would be open to if anyone wants to contact me about one."

Over 300 RBC Bank Branches Across Canada Now Offer Greater Independence for Canadians With Vision Loss — BlindSquare

CALEIGH NEVIN

305 RBC branches (about 25 percent of the Canadian network) recently introduced the BlindSquare app to their customers to offer greater independence for those with vision loss. It's estimated that 1.5 million Canadians identify as having some form of sight loss, which can be a barrier when entering unfamiliar locations such as shops, banks, new streets, etc. RBC has taken the innovative stance to change this with their recent integration with BlindSquare, the world's most widely-used accessible GPS app developed for the blind, deaf-blind, and partially-sighted.

"You need to be able to make intelligent decisions once you enter an unfamiliar location. That means relying on sensory clues other than vision to navigate the world around you," says Debbie, a longtime customer of RBC. "For instance, if I am in a mall, I'll listen for the sound of a water fountain, as that likely indicates I'm in a central location. The smell of a food court or the beeps of an ATM can also give me clues to where I am in proximity to other things."

Clayton Van Esch, an RBC executive, shares that the BlindSquare integration with the bank's branches was well worth the effort. "BlindSquare, along with its EVENT app, is more than a 'find your bank' tool. It's a doorway to greater independence and a lifestyle tool for blind and partially-sighted people," explains Clayton. "We often talk about being most helpful to our clients by being on our clients' path. BlindSquare and its EVENT app make that path accessible even when it cannot be seen."

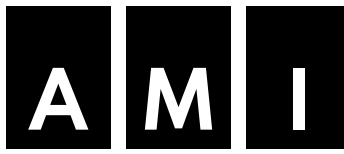
David Demers, President, CNIB Frontier Accessibility, shared that "Canadians living



with disabilities represent purchasing power of \$55 billion annually. These potential customers, along with their families and friends, frequent banks and other financial institutions. An accessible and inclusive establishment allows blind and partially-sighted customers more independence and security when dealing with sensitive information, such as their personal finances. An accessible experience draws in new customers and keeps them coming back again and again."

"Financial independence is an essential part of social participation. New technologies allow us to interact with our communities in a way never possible before," says David. "Now, with greater abilities to participate in the world around us, provided by socially-conscious corporations like RBC, blind people like me can better engage with and contribute to the society we are a part of. Obviously, the independence this technology brings provides me multiple benefits, but there is also an upside for our economy and the greater community."

We look forward to continuing to expand this program with our friends at RBC. Are you a banker who would benefit from RBC's BlindSquare integration? Anyone can download the free version of BlindSquare's EVENT app from the iOS App Store to assist in navigating throughout your community, likely including your local RBC branch.



TWO LIVE shows

to keep you entertained, informed, and connected with the disability community



NOW WITH DAVE BROWN

Start your day with *NOW with Dave Brown*. Tune in to AMI-tv weekdays starting at 9 a.m. ET for the latest news, entertainment, sports, and current events.

Kelly & Ramya

Kelly and Ramya, along with their team of contributors, complete your day with interviews and lively discussion about arts, entertainment and lifestyle issues that matter to you.

Tune in to AMI-tv and AMI-audio weekdays starting at 2 p.m. ET



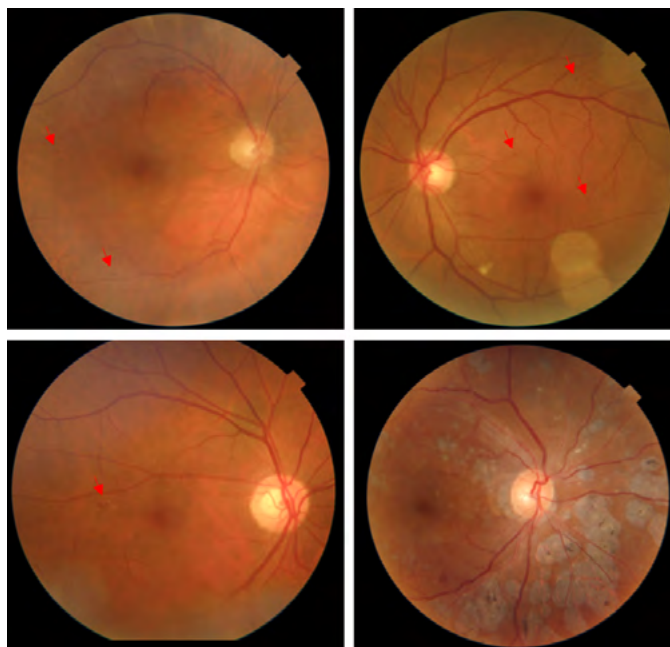
Stream AMI content now.
Visit us at AMI.ca or download the AMI-tv App

Canadian Ophthalmologists— Innovating for All

SPECIAL TO WHITE CANE MAGAZINE /
CANADIAN OPHTHALMOLOGICAL SOCIETY

Canada's vast geography has always posed challenges to the health care system's ability to provide care in sparsely-populated rural and remote areas. The delivery of comprehensive and timely eye care health has been no exception and there has long been a need for services in centres that patients can access at their convenience. The COVID-19 pandemic has highlighted the role that technology and innovative thinking can play in the delivery of health care. Ophthalmologists across the country embraced technology, including virtual care, to serve their patients at a time when accessing regular, in-person appointments was not feasible for many.

As part of the Canadian Ophthalmological Society (COS)'s mission to advocate for vision health for all Canadians, the COS Foundation (the Society's philanthropic arm) has made access to ophthalmological services in underserved, rural, or remote areas a primary focus and is currently designing and implementing innovative and concrete solutions for those living far from urban centres. An initial pilot study will be conducted in Western Canadian communities whose populations have traditionally encountered barriers to accessing timely and regular eye care. These include First Nations and migrant workers, among others. The model will partner with and build on services already available in the communities, namely diabetes centres. The goal is to condense an eye exam and diabetes check-up into a single appointment, thereby reducing patients' travel time and costs. Photos can be taken during patients' regular diabetes clinic visits without needing to first dilate their pupils. In addition, the photos do not need to be sent away for review and reading by an ophthalmologist. Rather, the images are read by a computer and an artificial intelligence (AI) algorithm is able to immediately determine whether diabetic retinopathy is present. If no retinopathy is detected, the patient is asked to return for screening at the appropriate interval



The top images show mild non-proliferative diabetic retinopathy, the bottom left shows moderate non-proliferative diabetic retinopathy, and the bottom right shows inactive proliferative diabetic retinopathy. Images via the *Canadian Journal of Ophthalmology*.

“There is an explosion of technology these days and the key is really to find ways to leverage its use to help better people's lives. It's not a replacement for the expertise of ophthalmologists, but rather a tool to expand our ability to take care of patients.”

– Dr. Vivian Yin, COS Foundation Task Force on Access

(usually one to two years). If retinopathy is detected, the patient is referred for an eye exam with an ophthalmologist. The overarching objective of this model is to increase adherence to vision screening in order to detect diabetic retinopathy in its earliest stages. Earlier detection and earlier treatment will save more patients' vision.

As we emerge from the global pandemic and our health care system adapts to respond to the many lessons learned, Canadians from coast to coast can be assured that ophthalmologists will continue to be at the forefront of innovation as a cornerstone of their commitment to deliver the highest-quality eye care for all.

Ophthalmologists are highly-trained eye physicians and surgeons, and the designated medical leaders in the eye care team. They specialize in eye and vision care, surgery and medical interventions, and the diagnosis, treatment, and prevention of serious eye diseases.

CNIB Steps Into the Way Forward

On the heels of its last strategic plan, Bold Dreams, Bright Futures, CNIB has created a new game-changing plan that's poised to influence real change in society for Canadians who are blind, partially-sighted, or deaf-blind. It's called The Way Forward, and the organization will be launching it to the public this fall.

The non-profit says the world has changed dramatically for people with sight loss over the last few decades, but the blind community continues to face significant barriers in every part of their lives – from work to education to the accessibility of built environments to social inclusion.

“CNIB cannot tear down these barriers alone,” says CNIB President and CEO John M. Rafferty. “We need allies. We need to shout our message from the rooftops and rally our advocates, like-minded organizations, political representatives, and the public to shout with us.”

Through its new strategic plan, The Way Forward, CNIB aims to position itself as a megaphone for people who are blind, partially-sighted, and deaf-blind, with the goal of reaching more Canadians with its message than ever before.

“For over 100 years, CNIB has worked alongside our community to move the needle on issues that affect them, inch by inch, day by day,” says Rafferty. “Now we're ready to be louder, more focused, and bolder than ever before.”

Taking direction from the blind community

In preparation to create this new plan, CNIB embarked on an extensive consultation process in



PHOTO BY: CNIB

CNIB President and CEO John M. Rafferty speaks with a large group of people affected by sight loss during the organization's 2021 community consultation process.

2021, reaching out to thousands of people with sight loss and their families across Canada – of all ages and from all walks of life.

“It was the largest consultation we've ever done,” says Rafferty. “Our goal was to better understand what our community wants and needs from us, and to create a strategic plan that drives us to meet those needs.”

CNIB staff travelled from coast to coast to coast and held 45 community meetings, delivered digital surveys to thousands of people in nine languages, and made thousands of phone calls – all to ensure their strategic plan would reflect the needs and goals of people who are blind, partially-sighted, or deaf-blind.

Some of the most prolific and challenging issues they heard about in those consultations were around lack of understanding about sight loss and accessibility within the general public, lack of accessibility when travelling, and lack of resources and support for children and families affected by sight loss.

From this feedback, CNIB identified commitments for its strategic plan:

- **Attitude Is Everything:** Increase understanding of blindness and dispel misconceptions about people who are blind, partially-sighted, or deaf-blind
- **Safe and Accessible Journeys:** Remove barriers and create

safe, accessible door-to-door journeys for all

- **Our Kids Will Thrive:** Give parents and children the support they need to excel in and out of the classroom

Rafferty points out that these goals may be ambitious, but The Way Forward isn't just a short-term plan. It's a pathway to a different future.

“The Way Forward is so much more than a strategic plan,” he says. “It's a manifesto for the future that CNIB and the people we serve are working to create together.”

Although its plan will technically span five years from 2023 to 2028, CNIB says it's just the beginning. It's a glimpse into a much larger vision – with an ultimate goal of creating a completely barrier-free society for the sight loss community in the decades ahead.

“We're no longer asking for change; we're demanding it,” says Rafferty. “We demand a future in which Canadians who are blind, partially-sighted, or deaf-blind can live in a world that feels fully inclusive to them; a world where our community has equitable opportunities in all areas of life, from education to work to social inclusion. That's what The Way Forward is all about, and we'll accept nothing less.”

To get involved with CNIB and support its new strategic plan, visit cnib.ca/support-us.

We Couldn't Do It Without You

The Canadian Council of the Blind (CCB) wishes to express its most sincere appreciation and gratitude to all our sponsors for their important contributions and ongoing support.

Your continued presence is necessary if the CCB is to continue to grow and develop. Therefore, it is important that you, as a group at the corporate level, as fellow

stakeholders and partners, and as individuals, understand our gratitude and appreciation for your confidence in and year-round support of the Council.

We couldn't do it without you. Together we are working to "change what it means to be blind," and that's important. Again, thank you!

CCB PARTICIPATING GOLD SPONSORS



CCB PARTNERS AND STAKEHOLDERS



FRIENDS OF THE CCB



THANK YOU



where
science meets **humanity**™

Biogen is proud to sponsor the Canadian Council of the Blind's 2023 Conference on Vision Health

Founded in 1978, we have pioneered multiple breakthrough innovations for some of the world's most complex and devastating diseases. At Biogen, our purpose is clear: to serve humanity through science while advancing a healthier, more sustainable and equitable world.

[biogen.ca](https://www.biogen.ca)





More accessible More sustainable More connected

VIA Rail is committed to being the most accessible mode of national and intercity transportation in Canada. As the first federal organization to submit its multi-year accessibility plan under the Canadian Accessibility Act, we're leading the way by making the experience more accessible and inclusive for all our passengers—from reservation to destination.



For more
information



™Trademark owned by VIA Rail Canada Inc.