THE CANADIAN COUNCIL OF THE BLIND

WINTER/SPRING 2024

WhiteCanadaThe Voice of the Blind[™] in CanadaMagazine

INSIDE:

Preventing Eye Injuries at Home and at Work Seeing Life Beyond My Glaucoma The Latest in AMD Research

AMD AWARENESS MONTH

February is Age-Related Macular Degeneration (AMD) Awareness Month. Learn more and get involved.

INHERITED RETINAL DISEASES, CAUSED BY GENE MUTATIONS, ARE CONDITIONS THAT LEAD TO VISION LOSS.



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President's Message



PHOTO: ANDRE MARTIN

This year is off to a great start after a busy and productive 2023. In 2024, the Canadian Council of the Blind (CCB) will be commemorating our 80th anniversary. I'm looking forward to this May, when we'll host our Vision Month Conference in Ottawa (and virtually) and celebrate our anniversary at the Gathering of Stakeholders following the conference.

This is also when we'll announce our 2024 President's Award and Person of the Year Award recipients. In 2023, these prestigious awards went to Mel Doris (President's Award), a long-time friend of the CCB and advocate for people with low vision, and Ian White (Person of the Year Award), a fierce advocate for the visually-impaired community and a shining example of how an individual with vision loss can achieve their full potential.



The exciting progress of Bill C-284

Looking back at 2023, I'm proud of how much we've accomplished, starting with exciting news from Parliament Hill. On October 25, 2023, Bill C-284, An Act to establish a national strategy for eye care, received unanimous consent as it followed legislative protocols through the House of Commons, and is now set to undergo its due processes through the Senate, where it received first reading on October 26, 2023. The Private Member's bill was introduced by the Hon. Judy Sgro, MP (Humber River – Black Creek) on June 14, 2022. I'd like to extend a special thanks to the Hon. Judy Sgro for her tireless efforts on behalf of the blind, deaf-blind, and partially-sighted community as well as the vision health community as a whole.

As the Hon. Judy Sgro said, "Our eyesight is precious. Without it, we are bound in countless ways: physically, socially, cognitively, and more. I'm pleased to report that Bill C-284 has been unanimously supported by the House of Commons and is currently being reviewed by the Senate. This is an important milestone and an incredible moment for the vision health community and all Canadians. I'm excited to see the finish line for our national eye strategy, which the community has awaited for so many years."

I would also be remiss not to thank the Hon. Judy Sgro for recognizing the CCB's assistance in her efforts in passing the bill. If you missed the Hon. Judy Sgro's speech in Parliament the afternoon of Friday, October 20, 2023, you can watch the video of her speaking in the House by following this link: http://tinyurl.com/673tv5kc.



The Honourable Judy Sgro, MP PHOTO: COPYRIGHT HOUSE OF COMMONS

Our conferences are a big success

2023 was an exciting year for CCB conferences. In May, during Vision Health month, we organized a conference that focused on treatments for eye diseases in Canada, now and in the future. The presenters, some of Canada's pre-eminent ophthalmologists, told us about new sight-saving treatments soon to be available in Canada, and provided us with an outlook on the future of vision health care. A second Vision Health Month conference was organized by the CCB Toronto Visionaries Chapter at the end of May. This forum provided an update on the progress that the combined Ontario Assistive Devices Program (ADP) stakeholder working group had made since its inception. Presentations were made by members of the working group, including members of the Ontario government bureaucracy and the CCB. In October, the third CCB conference of the year focused on the current state of vision health in Canada. With the CCB Report Card on Vision Health as the basis for the discussion, representatives of the major Canadian vision stakeholders gave us their view of what the future might look like within their domain. With three conferences in the planning stages, 2024 plans to be another banner year for CCB conferences.



Leading research initiatives from the CCB

Six years ago, Michael Baillargeon, Senior Manager of Eye Care Initiatives at the CCB, undertook the CCB's first research study. The study was commissioned in late 2018 by the federal government's Department of Innovation, Science and Economic Development's Accessible Technology Program. The study, released in March of 2019, reported on the need for accessible technology for people who are blind or partiallysighted. On the completion of this study, Baillargeon perceived the need to expand the CCB research effort and brought Dr. Keith Gordon, past Vice President of Research at the CNIB and the CCB's current Senior Research Officer, on board in late 2019. Since that time, the team has completed six important research studies: the Cost of Vision Loss and Blindness in Canada (published May 2021); an addendum to this study looking at the impact of the COVID-19 pandemic on the cost of vision loss and blindness (published August 2021); two surveys on the impact that the COVID-19 pandemic had on people living with vision loss (one conducted and reported on in April 2020, the second in October 2022); a Report Card on Vision Health in Canada (published October 2022); and a survey of people who are blind or partially-sighted, living in Ontario, concerning their experience with the Ontario government's ADP (published February 2022).



Dr. Keith Gordon

PHOTO: ANDRE MARTIN

Reforming Ontario's Assistive Devices Program

The data generated by the above studies supported significant advocacy campaigns on several fronts, by both the CCB and other organizations. A prime example of this are the evidence-based recommendations derived from our 2022 ADP Survey Report. Assistant Deputy Minister (ADM) Patrick Dicerni, in his letter dated April 21, 2022, to Baillargeon, received on behalf of the working group, accepted that the opinions of the survey report's respondents had been transformed "into tangible recommendations to improve the ADP," further stating that one of the primary goals of the working sessions would be "to gain consensus on how best to address the survey's recommendations in a feasible, sustainable way that will be the most beneficial to Ontario's vision loss community." ADM Dicerni ends his letter again thanking Baillargeon "for sharing your thorough, evidence-based survey report. The ADP appreciates the value CCB brings to the ADP and looks forward to a collaboration that will further benefit Ontario's vision loss community." The report's recommendations have been used as the basis for the Terms of Reference of the joint working group convened to reform the ADP. The CCB has led this initiative, with several key stakeholders. Discussions have been robust, and we are working with the hope that tangible results will emerge from this process in the coming months.

To be clear, Ontario's ADP is a wonderful program with great potential, but it requires significant reform if it is to adequately serve Ontarians living the experience of vision loss. Baillargeon states that the recommendations "made to the ADP are recognized as evidence-based, client-centred, informed, substantive, and reflective of the needs of Ontarians living with vision loss." In the current digital economy, people with blindness and partial sight increasingly rely on cutting-edge assistive technologies to transform their lives and to maximize their human potential, their independence, and their quality of life. But for many economically-disadvantaged people with sight loss, the transformative power of the latest emerging assistive devices and accessible digital tools is simply not affordable. To unlock the human potential and transform the lives of half a million Ontarians and over two million Canadians, we need fair and affordable access to a range of assistive devices.

Expanding the CCB's Mobile Eye Clinics

In 2024, we're looking to expand the CCB's Mobile Eye Clinic (MEC) program, which has delivered many benefits to the public and the council. Having completed more than 10,000 eye exams, MECs have been instrumental in developing our preventable eye disease programs and have helped us advocate for better eye care across the country. The program has also formed the basis for the launch of our research initiatives into blindness and how to prevent it, as well as into improving the quality of vision care and quality of life for those suffering from vision loss. A recent CCB and Fighting Blindness Canada study shows the cost of vision loss to the Canadian economy, and MECs can reduce this cost significantly while providing vision care to the underserved and underprivileged.

The CCB's Get Together with Technology Program continues to thrive

On another front, the CCB's Get Together with Technology (GTT) Program continues to be delivered by more than 20 local groups across the country with support from David Green in Ottawa and Corry Stuive, the CCB's National Program Coordinator. Novice and expert assistive technology (AT) users alike gather to share information on the latest trends, product reviews, handy tech tips, and more, all while focusing on the specific needs of blind and partially-sighted people. Most importantly, it's delivered by blind tech users to blind tech users, so the information being shared is always relevant and centred firmly on the needs of those who rely on AT to live their daily lives independently. If you want to get together with Android or iPhone users or those who use braille input/output devices, or to access the latest screenreader or screen-magnification software or the latest apps for the blind, there's a GTT group for you!

Looking forward at the power of AI

On an entirely different subject, I was privileged to be invited to the Optometric Leaders Forum in Ottawa at the end of January. Organized by the Canadian Association of Optometrists, the forum focused on artificial intelligence (AI), specifically on the impact that AI can be expected to have on the practice of optometry and vision health over the next few years. We heard presentations from various representatives of companies developing products using AI, ranging from the use of AI to enhance the diagnosis of eye disease to the use of AI to enhance practice management and patient triaging. I was surprised to learn that there's already a device approved by the United States Food and Drug Administration for the early detection of diabetic retinopathy. Al holds tremendous potential as a tool for early detection of most eye diseases, with the hope that early detection will in turn lead to early treatment and the prevention of vision loss.

Exciting times are ahead, and 2024 is going to be a big year for the CCB and the vision care community at large. Thank you so much to our sponsors, partners, volunteers, and community for your support. We couldn't do it without you.

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Jim Tokos National President Canadian Council of the Blind

Focus on Geographic Atrophy

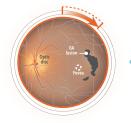
Geographic atrophy (GA) is the advanced form of age-related macular degeneration (AMD).^{1,2}



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 near-central and low-light vision.⁴

GA Disease Progression^{4,5}



Some loss of near-central, low-light vision



Loss of

near-central,

low-light vision

Loss of near-central, low 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



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EDITORIAL



PHOTO: ANDRE MARTIN

Improving Accessible Travel Just Makes Sense

According to Statistics Canada, eight million people aged 15 or older identify as a person with a disability in Canada, and as the population grows older, that number is expected to rise significantly.

That's 27% of the population and like the rest of Canadians, this group aspires to get out of their homes and move around – whether within their local communities or travelling the world. Persons with disabilities like to get out and go, just like everyone else!

Unfortunately, travel for this group is too often met with obstacles. Whether on local transit, such as buses or light rail, or other means of transport such as airplanes, taxis, or ridesharing services like Uber or Lyft, issues often arise regarding accessibility.

And when our community hears stories of someone being refused a taxi ride because of their service dog, accessibility features such as audible bus announcements not working, or airline passengers with a disability being mistreated, we're not surprised. This is because the majority of us have faced these issues ourselves when travelling.

In fact, Statistics Canada found that 63% of the 2.2 million people with disabilities who used federally-regulated transportation in 2019 and 2020 faced a barrier.

We know that the federal government has set a goal of being barrier-free by 2040, but we also know that more needs to be done to remove the obstacles that make travelling difficult.

Fortunately for us, organizations such as the Canadian Council of the Blind (CCB) are advocating tirelessly on our behalf to improve accessibility for travellers with disabilities. This is evident in relationships such as the one between the CCB and VIA Rail, where the two organizations have worked hard to enhance train travel and ensure people can travel autonomously. Travellers can now access braille menus, spacious train cars, service animal relief areas, and trained staff who are knowledgeable on issues faced by travellers with disabilities.

Programs such as the CCB's Get Together with Technology (GTT) give members of the blind and visually-impaired community an opportunity to chat about tips and tricks for travelling in a safe space, where ideas can be discussed and shared. GTT coordinators are happy to show members the latest smartphone apps that can assist in travel and to explore these options in a group setting. This kind of peer support is so beneficial to members of our community who want to get out there and experience what the world has to offer.

And a note to the travel industry – it's in your best interest to work with the disabled community to improve accessibility. As mentioned earlier, this population is only going to grow and if you can improve the travel experience, this segment of the population will spend money on your services.

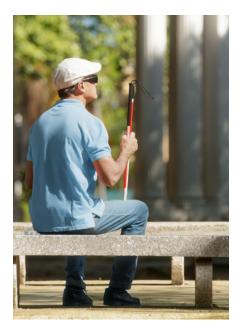
It's so important to remain vigilant and to continue to advocate for our rights and to be treated as equal citizens. White Cane Week provides an excellent opportunity to raise awareness of the needs of the visually-impaired community, as well as to showcase our many abilities.

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.

Mike Potvin Editor 2024 White Cane Magazine

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

he 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 nationallyregistered 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 partiallysighted. In bringing together Canadians with lived experience of vision loss, the CCB maintains a vibrant network of active members in 73 chapters across Canada. Each chapter is unique to its geographic area, community-based, locally-organized, and volunteerdriven 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 selfesteem 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 <u>www.ccbnational.net</u>.



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 partiallysighted 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.

Preventing Eye Injuries at Home and at Work

DR. KEITH GORDON

id you know that every day about 2,300 Canadians sustain an eve injury that requires medical attention? A study conducted about 12 years ago showed that every year, about 2% of Canadians have an eye injury that requires medical attention. The study also showed that approximately one quarter of all eve injuries had resulted in taking time off from work or school. Many of these injuries can be prevented by something as simple as wearing protective eyewear.

When the eye injuries were analyzed further, it was found that the number of eye injuries occurring at home and at work was approximately the same, each location accounting for about 800 injuries, the rest occurring outside of the home or workplace. Only 8% of eye injuries were due to sport, probably because people are now protecting their eyes while playing sport. But it appears that we don't protect our eyes to the same extent when doing things around the home or at work.

The importance of safety glasses

The most important thing we can do to protect our eyes both at home and at work is to wear appropriate eye protection.



There are many types of eye goggles or safety glasses that one can wear to protect their eyes. The Canadian Centre for Occupational Health and Safety provides a full listing and a description of the best safety glasses and eye protection for different occupations. This information can be accessed at the following link: http://www. ccohs.ca/oshanswers/prevention/ ppe/glasses.html.

The best safety glasses are those that are made with polycarbonate lenses and are Canadian Standards Association (CSA) certified. Many safety glasses are available as sunglasses with the ability to absorb ultraviolet light. This means that you have the opportunity to wear these glasses outdoors to protect your eyes from injury while at the same time protecting them from long-term damage from the sun's ultraviolet rays.

It's recommended that people working with chemicals use protective goggles. Another study conducted a few years ago showed that about half the eye injuries due to chemicals were incurred by people wearing either safety glasses or safety prescription glasses, while none were incurred by people wearing eye goggles.

Eye safety at home

The following are some of the things we can all do to prevent eye injuries around the home. A more comprehensive list is available from the Canadian Association of Optometrists at https://opto.ca/eye-health-library/ eye-safety-home.

- It's essential to wear eye protection whenever doing any work with tools around the house, for example hammering a nail or using a lathe, an electric saw, or a screwdriver. Pieces of wood, metal, or plaster can so easily shoot into your eye.
- Wear safety glasses when working in the garden. Eye injuries are often caused by tree branches or debris that shoot out of a lawnmower.
- Ensure all spray nozzles are pointed away from you before you press them.
- Read instructions carefully when using harsh chemicals and wash your hands thoroughly afterward. Wear goggles where appropriate.
- Use grease shields on frying pans.
- Use opaque goggles to avoid burns from sun lamps.
- Be especially careful when using "S" hooks and bungee cords.



 Point the sparkling wine or champagne bottle away from you when uncorking it. An eye injury is nothing to celebrate.

Eye safety in the workplace

Most workplaces have strict protocols for eye protection for certain occupations, such as welding, laboratory use of chemicals, and so on.

Make sure you follow these protocols and always use your safety glasses or eye protection. If you're a welder, make sure you wear your eye protection rather than just holding it. Harmful radiation can enter the eye from the side of a loosely held welding helmet. If you're a chemist, wear safety goggles every time you work with chemicals, not just during the week after one of your colleagues had an accident or a fire.

Now that you're practising eye safety, make sure that those around you are doing so as well, both at home and in the workplace. We all have a role to play with respect to reducing the significant social and personal costs associated with eye injuries.





White Cane Week Conference **Attend Live or Virtually**

Tuesday, February 27, 2024 | 10 am – 2 pm

To learn more and register: fightingblindness.ca/viewpoint/

On behalf of the Canadian Council of the Blind and Fighting Blindness Canada, we'd like to invite you to a special conference designed to recognize Age-Related Macular Degeneration (AMD) Awareness Month and the results of the Canadian Survey on Disability 2022.

Online and in person, Christ Church Cathedral, The Great Hall, 414 Sparks St., Ottawa, ON K1R 0B2

Continental breakfast from 9:15 am and a light lunch will be served.

The conference will be split into two sessions.

10:00 am - 12:00 pm

View Point: Ask the Expert about Age-Related Macular **Degeneration (AMD)**

Fighting Blindness Canada presents a special event to recognize Age-Related Macular Degeneration (AMD) Awareness Month. Join us for a full morning of interactive sessions with doctors and people living with AMD to learn more about this prevalent eye condition that affects over 2.5 million Canadians. Sessions will include a presentation about AMD by retinal specialist Dr. Bernie Hurley, a lived experience panel, and an opportunity for you to ask your questions directly to the doctor.

12:45 pm - 2:00 pm

Canadian Survey on Disability 2022

The Canadian Council of the Blind presents a panel discussion with researchers from Statistics Canada about the 2022 Canadian Survey on Disability. In this engaging session, panellists will discuss how this data was collected, why it's important, and what the results tell us about the prevalence of disabilities, including seeing disabilities, in Canada.

If you require assistance registering, please contact us at education@fightingblindness.ca or by phone 1.800.461.3331 ext. 246.

OPINION

Digital Marginalization and the Problem of Two-Part Solutions

IAN WHITE

he comedian Chris Rock once mused that there was no need for gun control. The solution to all of the gun violence that plagued America was to make guns freely available, but to make bullets cost \$5,000 each. He was pointing to the idea that a gun, to be an effective weapon, needs bullets. It's a two-part system. Neither part, the bullets by themselves nor the gun itself, can function as a weapon without the other.

Recently, federal and provincial governments have committed to massive investments in internet infrastructure to ensure all Canadians have access to the digital economy. In 2021, the federal government announced \$1.7 billion to build internet infrastructure to bring digitally marginalized rural and northern communities online. And the Ontario government announced its high-speed action plan, Up to Speed, committing an additional \$1 billion in infrastructure funding for the same purpose in Ontario. Both levels of government agree that access to high-speed internet is no longer a luxury but a basic necessity, and the fact that not all Canadians have full access to high-speed internet services is simply "unacceptable."

Getting all marginalized Canadians connected to the digital world means they can fully participate in the same daily activities we all take for granted: the digital economy, the political process, education, banking and finance, news and entertainment, accessing government services (including the supports that are intended to lift those in most need out of poverty), and much, much more. But funding internet infrastructure is only addressing one part of a two-part system. There must be an internet to connect to, certainly. But digitally-marginalized citizens must also have access to the devices capable of making that connection. Without an internet-capable device, no one can connect to the internet, and through it, the digital



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economy, no matter how freely available the highspeed network. And this second part of the two-part system is being ignored by both the federal and provincial governments.

The blind and low-vision community is just as marginalized as rural and northern communities with regard to their lack of digital access – not by geography or the unavailability of internet infrastructure, but by stigma, socioeconomics, and the high cost of internet-capable devices. This community is excluded from the digital economy by lack of affordable access to the second part of the two-part system: fully accessible internet-capable devices like computers, laptops, tablets, and smartphones. Yet despite the billions being allocated to address the infrastructure side of the equation, little is being done to support the availability of accessible internetcapable devices for those who need them.

Ontarians living with low vision and blindness are an economically-disadvantaged community. People with seeing disabilities are between 60% and 70% chronically unemployed or underemployed. Many rely on punishingly meagre disability pensions, publiclyfunded supports, or restrictive retirement incomes to live. They're among the least able to afford the kinds of assistive technologies that could transform their lives and put them on a more level playing field with their sighted peers.

The Ontario government attempts to address this marginalization through funding the Assistive Devices Program (ADP), which is designed to help those with a variety of disabilities to afford the specially-designed devices they need to increase their independence and improve their quality of life. The ADP offsets 75% of the pre-tax cost of those devices it deems the necessary assistive devices required to help disabled Ontarians meet their basic needs. Some of these To address the digital marginalization of people with disabilities, governments need to understand that addressing one part of a two-part problem only serves to further disadvantage digitally-marginalized people, leaving them further behind.

funded "visual aids" include computers, laptops, and tablet computers, all of which are internet-capable.

Yet, the ADP does not fund these devices because they're capable of accessing the digital world. In the ADP's view, computer systems, laptops, and tablet computers are merely "writing tools" to overcome a print disability, nothing more. The internet capability of these devices is secondary, and irrelevant, from the ADP's perspective. The ADP does not fund smartphones, which are essentially pocket-sized portable computers with full internet capability, the functional equivalent of a laptop or tablet.

As society – including government at all levels – shifts at an increasingly accelerating rate toward all and only digital access, and as more and more accessibility tools for people with blindness and low vision are exclusively designed for use with – and can only be accessed with – internet-capable devices, the ADP's policymakers have it exactly backwards. It is that these devices are internet-capable that allows them to be useful in meeting the needs of disabled people in our current society. The fact that they're also useful as writing tools to overcome a print disability is what is secondary, though not irrelevant.

Of the ADP's annual budget of over \$600 million, the total amount allocated to supply those with vision disabilities the essential assistive devices they need to live independently is a meager \$2.9 million. And the amounts actually spent on incidentally internet-capable devices authorized as "writing aids" to blind and low-vision clients is a tiny fraction of that. Compared to the \$2.7 billion to build internet infrastructure, this total dwindles to insignificance.

Smartphones are the accessibility tool of choice used by 76% of the CNIB Foundation's blind and lowvision clients. In the absence of a government-funded solution, the CNIB runs the Phone It Forward program, providing refurbished smartphones to its clients for free. But the CNIB can only process between 300 and 400 phones annually in Ontario and has waitlists in the hundreds. Compare this to the 466,000 Ontarians who live with a seeing disability. The CNIB's Phone It Forward program is laudable, but simply cannot meet the demand. Access on this scale can only be accomplished with the will of government.

To address the digital marginalization of people with disabilities, governments need to understand that addressing one part of a two-part problem only serves to further disadvantage digitally-marginalized people, leaving them further behind.

The ADP could do much in this regard by incorporating smartphones into its list of funded devices for its blind and low-vision clients, and by altering its policies to view digital access as a priority need.

Governments are spending billions of tax dollars to ensure that we all have equal access to digital infrastructure. But both levels of government must also be willing to address the second part of the problem: funding the accessible internet-capable devices that are the keys to unlocking that world, and the potential of hundreds of thousands of Ontarians. The impact of a relatively small investment could have stunningly positive consequences for the chronicallymarginalized blind and low-vision population.

Chris Rock was right. To make a weapon – one capable of breaking the cycles of poverty and marginalization experienced by Ontarians – and all Canadians with seeing disabilities – we need both parts of a two-part solution. We need internet infrastructure, and we need the accessible devices to access that infrastructure, to give all of us an equal opportunity to share in the advantages and benefits of the digital world. Anything less is simply "unacceptable."

Improving Eye Health One OCT Scan at a Time

With over 100 stores now open in Canada, Specsavers' goal is to care for 1 million Canadians in 2025

By Specsavers

"Advanced clinical equipment such as OCT emphasizes how Specsavers is committed to giving eyecare professionals the tools they need to be successful in delivering patient care."

Specsavers, an optometrist-owned and -led company was founded on the vision that eyecare and eyewear should be accessible to everyone. The company, which entered the Canadian market in late 2021, recently celebrated a significant milestone as it surpassed the opening of 100 Canadian locations.

"Our goal is for every Canadian who walks through our doors to have quality eyecare, which is why every Specsavers location is equipped with OCT, a 3D eye scan that allows an optometrist to look at the back of the eye to get a deeper understanding of a patient's eye health," said Bill Moir, Managing Director, Specsavers Canada. "Early detection is critical as 75 per cent of vision loss is preventable and treatable, which is why optometrists in the Specsavers



Specsavers optometry and retail partners attend an Ontario regional meeting, April 2023

network include this powerful OCT technology as part of every standard eye exam."

Specsavers is currently operating in British Columbia, Alberta and Ontario, with plans to open locations in Manitoba in summer 2024. As the fastest growing network of eyecare professionals in Canada, the Specsavers network includes more than 200 optometrists, 250 licensed opticians and 1,000 eyecare consultants who are committed to prioritizing patient care and the Specsavers purpose of 'changing lives through better sight.'*

Specsavers recognizes cost and access are barriers that Canadians face when trying to maintain their eye health or improve their vision. To put purpose into action, Specsavers removes barriers by offering highquality glasses at affordable prices and supporting clinics to include OCT as part of their standard eye exam.

With every additional store opening, clinics within Specsavers are caring for the eyecare and eyewear needs of over 100 Canadians per week using OCT. OCT aids in the early detection of sight-threatening conditions such as glaucoma, diabetic retinopathy and more. The company is on track to care for a million Canadians a year by 2025.

"Through the consistent use of OCT, we're focused on efficient and effective referral pathways between optometrists and ophthalmologists to manage and co-manage their patients. This means ophthalmologists can focus their time on patients who need their care the most," said Naomi Barber, Clinical Services Director at Specsavers. "We understand the critical role of technology, for this reason, optometrists in our network are supported to practice to their full scope and make timely care more accessible, wherever possible."

"Our optometrist-led steering groups, in each province where we operate, and access to advanced clinical equipment such as OCT are just some examples of the areas Specsavers focuses on to give eyecare professionals the tools and support they need to deliver outstanding patient care," added Barber.

"As Specsavers surpasses the opening of our 100th store in the country, we intend to continue to show Canadians our unwavering commitment to their eye health," said Moir.

*Based on LinkedIn company reports on new profile position between August 1, 2022 – July 31, 2023.

CC I am honoured to be a part of this progressive and knowledgeable group of doctors. $\rm Score$





Specsavers

Undoing Pervasive Myths about Blindness: See Me, Please

LUNA BENGIO, SENIOR ACCESSIBILITY CONSULTANT

A ttitudes toward blind people have evolved over time. Advocacy efforts and advancements in technology are opening up possibilities for blind people to live the life they want and challenge stereotypes.

In Canada, I believe that we have an accessibility and inclusion moment to seize to drive historic and enduring societal change.

Yet, how often, as a blind person, do I sense the curious or pitying looks? How many times will someone come up to me and tell me how amazing they think I am, just because I crossed a busy street?

In our modern society, the "hero" or "victim" syndrome continues to stick to people with disabilities. I strive to dispel these myths as a blind individual and an accessibility professional. There is, however, a grim reality that is exceedingly difficult to accept. Many people don't truly see me.

This phenomenon usually manifests itself in the form of a three-way conversation: I'm sitting at a restaurant, for example, with a friend or family member. The waiter will ask my companion, "What would she like to eat?" I can't promise that I always react calmly to these kinds of situations. Often, I will intervene with a smile and say, "I would like so and so, please." Sometimes someone, especially one of my children, will reply, "Why don't you ask her directly?" but inevitably I feel excluded and invisible. Variations on this theme occur when, perhaps because I'm not making eye contact with them, some people do not acknowledge my presence or include me in the conversation.

To combat this kind of insidious discrimination, blind or sighted alike, it comes down to upholding the inherent right of every human being to be treated with dignity and respect, to make their own choices, to succeed or fail, and to function differently. In the words of my wise six-year-old granddaughter, "You see with your hands, right?"



So, let's get at some pervasive myths about blindness:

1. Blind people are helpless.

Rather than outlining all the reasons why this isn't true or listing my accomplishments, let me just ask: do you know anyone who never needed help?

2. Blind people cannot work.

A colleague once told me that I could never do her job. Others think that specific jobs should be created for people with disabilities. Such condescending beliefs explain, at least in part, the low employment rate of blind people in Canada. While despite technological progress, you wouldn't want me driving a truck or piloting an airplane, as a hiring manager, consider the next blind applicant with openness, focus on their skills, and equip them for success. You will benefit from their lived experiences and resilience.

3. Sight is indispensable to live a fulfilling and productive life.

Would I like to see? Of course! Images like a sunset over the ocean cannot quite be replicated in a text description. However, accessible maps and documents, movies with audio description, and verbal announcements in the transit system go a long way to foster independence and create opportunity. People are disabled when they encounter a hostile environment designed for the illusive average person. Physical, sensory, or cognitive barriers can be eliminated through planning and universal design.

Most importantly, it's our culture that needs to change. I'm a multi-faceted individual. While blindness is one of my characteristics – one I embrace, for it affords me a variety of rich life experiences – it does not define me. I would like people to see the person I am, to set aside preconceived ableist notions, and to simply see me.

Ask an Ophthalmologist:

Age-Related Macular Degeneration

Age-related macular degeneration (AMD) is the leading cause of blindness in Canada. Below, we share a condensed article from ophthalmologist Dr. David Maberley, discussing the most important things you should know about AMD.

What is AMD?

AMD is a condition that affects the retina and, specifically, the macula. The retina is a structure at the back of the eye made of lightsensitive tissue. It acts like the film in a camera; it converts light into a signal that the brain interprets as an image. At the centre of the retina is a small area called the macula that allows us to see fine details clearly.

AMD happens when cells of the macula begin to break down or deteriorate, causing loss of central vision. With AMD, one loses the sharp, detailed vision necessary for activities like driving, reading, and recognizing faces.

What's the difference between wet and dry AMD?

To understand the two types of AMD, you can think of the retina and underlying cells as a sidewalk. It starts as a smooth, paved sidewalk, but over many decades, the sidewalk starts to crack and crumble. This is like what happens with dry AMD. The cells of the retina start to deteriorate. Symptoms of vision loss occur gradually and slowly worsen over time.

Sometimes, small trees start to grow through the cracks in a sidewalk. These can push apart the edges of the sidewalk and cause a lot of damage in a short amount of time. This is what happens to the eye with wet AMD. Blood vessels can start to grow through weakened areas under the outer retina. These vessels bleed and leak fluid, causing swelling and scarring, which leads to vision loss.

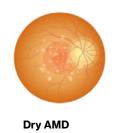
I've just been diagnosed with wet AMD. How long will I need treatments for?

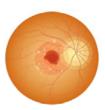
Treatment for AMD is centered on the use of anti-vascular endothelial growth factor (anti-VEGF) injections that help slow the disease's progression. Treatment for wet AMD requires a long-term commitment and consistent follow-up. Typically, after the first few monthly injections, anti-VEGF drugs are given less frequently and are often only needed every 2–3 months.

What research is being done?

It's certainly an exciting time for AMD, with innovations on the horizon that will improve AMD care in Canada:

- For wet AMD, next-generation anti-VEGF drugs are in development that may be more durable than currently-available options. These would mean patients wouldn't need to receive injections as often.
- New treatments will be coming to market soon for geographic atrophy (GA) – a currently untreatable late-stage form of dry AMD.





Wet AMD Abnormal blood vessels Blood and fluid

Other types of therapies are in early investigational stages:

- Gene therapy is being studied to help the eye produce its own anti-VEGF.
- Stem cell therapy is being investigated to replace the damaged retinal cells. These cell transplants would potentially "repave the sidewalk," if you will. Other areas of advancement are in diagnostics and monitoring. Fundus autofluorescence (FAF) is an imaging technique that's useful for more clearly defining the areas of damaged cells in dry AMD. The images can be coupled with AI (artificial intelligence) algorithms to help track disease progression and monitor lesion growth.
- Inexpensive monitoring technologies that detect distorted vision are also being studied in clinical trials. These devices have the potential to be used in patients' homes, with data relayed directly to their ophthalmologists so that follow-up plans can be adjusted accordingly.

With these and other promising advancements, the future of AMD management is looking bright.



David Maberley, MD, is Head, Department of Ophthalmology at The Ottawa Hospital and is currently President of the Association of Canadian University Professors of Ophthalmology (ACUPO). This article in its entirety can be found at <u>seethepossibilities.ca/ama</u>.



FIGHTING Blindness Canada Canada

The Latest in Age-Related Macular Degeneration Research Funded by Fighting Blindness Canada

Age-related macular degeneration (AMD) is the leading cause of vision loss in people over the age of 55, affecting approximately 2.5 million Canadians. In AMD, central vision is affected, making it harder to do activities like reading, driving, and distinguishing faces. In February, AMD Awareness Month, we're sharing some of the trailblazing AMD research that Fighting Blindness Canada (FBC) is supporting.

Dr. Matthew Quinn (Ottawa Hospital Research Institute)

Changes in the microbiome can be caused by inflammation and have been linked to wet AMD. Dr. Quinn is using populationlevel databases to determine if there's an association between common clinical events that disrupt the microbiome and AMD progression. This knowledge may help to develop new treatments or prevention strategies for AMD. Dr. Quinn is one of our recentlyannounced Clinician Scientist Emerging Leader Award winners.

"We're learning that it's critical to understand the links between systemic health and vision loss in order to develop new treatments and optimize care for patients with AMD," explains Dr. Quinn. "This award will fund research that will allow us to better characterize how systemic health events impact the risk of macular degeneration progression."

Dr. Andras Nagy (Lunenfeld-Tanenbaum Research Institute)

In wet AMD, blood vessels can grow uncontrollably and leak fluid into the eye, damaging retinal cells and causing vision loss. Antivascular endothelial growth factor (anti-VEGF) injections into the eye can reduce blood vessel growth, but do not restore vision caused by lost retinal pigment epithelium cells. Dr. Nagy is trying to develop a vision-restoring cell therapy for advanced AMD. His team is testing whether new retina cells that act as anti-VEGF producing factories can help restore vision and control blood vessel growth.

Dr. Sachdev Sidhu

(University of Waterloo)

The blood-retinal barrier (BRB) is important for proper retinal function and can be disturbed in eye diseases like AMD and diabetic retinopathy (DR), leading to vision loss. Dr. Sidhu has developed a new antibody treatment (EYE103) that has the potential to restore the BRB and help improve vision for those with AMD or DR. With funding from FBC, Dr. Sidhu has now moved this treatment into a Phase 1 clinical trial to test whether the potential treatment is safe.

To learn more about FBC-funded research, visit <u>fightingblindness</u>. ca/research/fbc-funded-research.

Do you have eye health related questions? Contact Fighting Blindness Canada's Health Information Line:

healthinfo@fightingblindness.ca |1.888.626.2995



Home Sweet Home: Safeguarding Wellness with Falls Prevention

SHANE GUADELOUPE

A home serves many roles. A home is a repository of memories, a sanctuary, a venue for gatherings, and, increasingly, a makeshift office. However, it can also harbour hazards, pose safety issues, and even become a prison of isolation.

Falls at home, a leading cause of unintentional injury hospitalizations, affect all ages and result from factors like reduced depth perception and visual acuity.

Sight loss awareness in falls education (SAFE)

Fortunately, since 2022, residents of British Columbia have had access to a falls prevention program through Vision Loss Rehabilitation Canada (VLRC). The non-profit health care organization provides specialized rehab for people with vision loss and offers SAFE, a seven-week fall prevention program addressing unique risks tied to vision loss. Individuals have the option of participating virtually or in person at VLRC's Victoria office.

According to Matt Ellies, Manager, Healthcare Integration for VLRC in B.C., SAFE has made a substantial impact on the lives of VLRC's clients.

"One of our clients, 'Jane,' in her early 80s, had a fear of falling that hindered her daily activities and led to social isolation," shared Ellies. "Through the program, she learned techniques for staying safe at home, which gave her the confidence to venture out more. Furthermore, she forged a connection with another participant who lived close by. As a result of her newfound confidence and friendship, she's leaving the house frequently for walks and together they participate in other health programs."

Reducing the burden on health care systems

For older adults, a fall can precipitate a hip fracture, triggering a cascade of health, mobility, and independence issues. By preventing falls, VLRC enhances and extends clients' lives.

A hallmark of the SAFE program is that it alleviates the burden on the health care system. By decreasing the need for hospitalization, SAFE plays a part in reducing two of the province's major issues: health care costs and overcrowding in hospitals.

A home as a healing haven

Research shows that people recuperate faster when discharged to their homes rather than remaining in a hospital. VLRC has been offering the Rapid Response Program, also known as the Urgent Referral Pathway, in B.C. since 2022. This short-term program, triggered by referrals from the acute or inpatient sector, is for people with confirmed vision loss that jeopardizes their ability to return home. VLRC promptly provides these individuals with essential vision-related clinical interventions.

"Currently, one to two clients per week are referred through our Urgent Referral Pathway in the Lower Mainland," shared Ellies. "These clients undergo an assessment by our occupational therapists before receiving support from the rest of our team."

PHOTOS: VLRC PHOTO LIBRARY



Matt Ellies, Manager, Healthcare Integration for VLRC in B.C.



VLRC orientation and mobility specialists teach clients with vision loss how to be safe at home and prevent falls.

Coordinated care for holistic well-being

By collaborating with hospitals and community service providers, VLRC plays a pivotal role in supporting hospital discharges.

"We've built great relationships with service providers in B.C.," Ellies conveyed, "which ensures our mutual clients receive high-quality, coordinated care."

VLRC strives to be a beacon of safety, offering programs that not only prevent falls but also promote healing and independence within the comforting walls of one's home.

<text>

Biogen is proud to sponsor the Canadian Council of the Blind's 2024 White Cane Conference

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Seeing Life Beyond My Glaucoma

Laura Feltz featured in a UN eye health photo exhibit

am one of an estimated 728,000 Canadians living with an eye disease often called the "silent thief of sight" – glaucoma.¹ It can develop in one or both eyes. In most cases, there are no early symptoms that you can detect, which is why regular eye exams are crucial.² While glaucoma awareness and treatments continue to evolve, it is still one of the leading causes of sight loss. I know that glaucoma waits for no one.

No one ever thinks about experiencing sight loss. Looking back on my vision loss journey, I realize I was focused on information and test results from the glaucoma specialist. I felt compelled to stabilize the sight I had. I stepped over the jumbled emotions I was feeling at the time. I didn't allow myself to grieve the sight I was losing.

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2 https://www.fightingblindness.ca/eyehealth/eye-diseases/glaucoma/



UNITED NATIONS 2030 IN SIGHT PHOTO EXHIBITION

Organized by the International Agency for the Prevention of Blindness

Fortunately, I'm surrounded by a supporting community and a brilliant healthcare team who have helped me through this experience. I wasn't going to let glaucoma defeat me. I finally gave myself the space and grace to acknowledge my emotions and grieve the life I thought I'd have as a sighted person. I learned that beyond the ambiguous grief of living with vision loss, there is still hope. There is power in my voice, and I was going to use it to raise awareness of eye diseases and encourage support for emotional health.

I had the distinct honour of being included in the United Nations' (UN) <u>2030 IN SIGHT photo</u> <u>exhibition</u> organized by the <u>International Agency for</u> <u>the Prevention of Blindness</u>. My photo was displayed in the hallways of the UN headquarters in New York, to personalize vision loss through the eyes of those living with it.

2030 IN SIGHT visually shows how accessible, available, and affordable eye health has the potential to improve the lives of millions of people around the world. My image highlights independence and

is linked to <u>UN Sustainable Development Goal 11</u>: Sustainable Cities and Communities. Eye care access for everyone could remove some barriers visually impaired people face helping make our communities safer and more inclusive.

Looking ahead

With this image, and in sharing my story, I hope to mobilize our community to seek support as they navigate their emotional eye journeys. You are not alone. There is support and valuable resources like <u>Fighting Blindness Canada</u> and the <u>Canadian Council</u> <u>of the Blind</u> for you and your loved ones.

While vision loss may impact you, it doesn't define you.



Laura Feltz is a women-centred coach who lives in downtown Toronto and is an active advocate for our vision loss community.



This content is proudly supported by AbbVie Canada.

Battling Myopia

How independent optometrists in the Specsavers network are working together to battle the growing global health concern



Dr. Maegan Folk, ob Optometry Partner Specsavers Orchard Park



Dr. Ramandeep Toor, oD Optometry Partner Specsavers Londonderry



Dr. Theodor Buzea, op Optometry Partner Specsavers Southcentre

By Specsavers

The World Health Organization declared myopia a global public health concern, with approximately half of the global population predicted to have myopia by the year 2050¹. Untreated myopia can lead to serious vision conditions later in life such as myopic maculopathy, retinal detachments, cataracts and glaucoma.

Given that myopia progresses mainly during childhood, there is a key window to intervene with preventative strategies, when the eye is more susceptible to growth and subsequent vision changes. This can reduce the risk of a patient developing sight-threatening conditions in adulthood due to the structural changes of the eye.

Optometrists within the Specsavers network raised an interest in introducing myopia management into their practice. Specsavers engaged its Optometry Steering Groups, a committee of independent optometrists in each province, on developing a training program with the option to introduce it to their practice.

The training program was designed alongside industry leaders to allow optometrists, opticians and their teams to receive comprehensive training to provide myopia management care and products. Specsavers interviewed Drs. Ramandeep Toor, Maegan Folk and Theodor Buzea on their involvement with the Optometry Steering Groups and myopia management.

Why was introducing myopia management into your clinic important?

Dr. Toor: After the pandemic, with work-from-home and more screen time, I was noticing that there was a significant increase in myopia. I grew up very myopic and I don't want my patients to have that struggle.

Dr. Folk: Myopia is becoming more prevalent and will impact a growing number of people. Myopia control is something I've always wanted to incorporate into my clinic. Specsavers gave me the tools and they brought the initiative to life. My clinic was one of the pilot clinics; it was fun to learn about it, bring it on and help start the initiative.

"Myopia is becoming more prevalent and will impact a growing number of people."

– Dr. Folk

¹Nouraeinejad A. More Than Fifty Percent of the World Population Will Be Myopic by 2050. Beyoglu Eye J. 2021 Dec 17;6(4):255-256. doi: 10.14744/bej.2021.27146. PMID: 35059569; PMCID: PMC8759558. 2.Holden BA, et al. *Global Prevalence of Myopia and High Myopia and Temporal Trends from 2000 through 2050*. Ophthalmology, 2016. 123(5): p. 1036-42.



Dr. Buzea: I had been doing myopia management for a few years before becoming an Optometry Partner with Specsavers. I wanted to make sure that I was offering it again when I moved my practice to Specsavers Southcentre because I had seen the benefits to patients.

Would you have any recommendations for other optometrists considering myopia management?

Dr. Buzea: If you're feeling hesitant about myopia management, do some research. You'll quickly realize why it's so important for your patients.

Dr. Toor: Incorporating myopia management within your clinic is a huge asset to have. If you can implement myopia control strategies early on, you can make a big difference for your patients. *"If you can implement myopia control strategies early on, you can make a big difference for your patients."*

– Dr. Toor

Can you describe the purpose of the Optometry Steering Group?

Dr. Folk: The purpose of the Optometry Steering Group is to help develop the clinical road map for optometrists within the Specsavers network. I wanted to be a part of it to help guide how optometry will look in Canada. Specsavers does a good job of collaborating with us and supports the needs of our practice. **Dr. Toor:** We are a group of optometrists who specialize in constantly evolving the scope of practice. The group discusses developments and how we can make further advances in our clinics. We also discuss the trajectory of optometry and share our best practices with one another.

Dr. Buzea: Being part of the **Optometry Steering Group means** that we can run projects and pilots. This allows Specsavers to go forward and present to the network of optometrists so they have the opportunity to consider incorporating new initiatives into their practices. I want to make sure that we're providing premium care. Not just the golden standard, but going above and beyond. As part of the steering group, I want to be responsible for helping provide newer and better technologies to patients.

Providing tools and resources to optometrists in the Specsavers network can help empower eyecare professionals to get ahead of the curve to change the predicted trajectory of myopia. Many of the teams have already reported impressive numbers of patients receiving this care. Together we're helping to make an impact in changing lives through better sight – not just in the short-term, but also in the future.

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Future Focus: Al in Eye Care

DR. MARTIN SPIRO President, Canadian Association of Optometrists

ately, Artificial Intelligence (AI) in eye care features prominently in continuing education programs, research topics, and discussions within leadership and regulatory circles. The tools that increase efficiency in our daily activities also have implications for eye care delivery. Every year the Canadian Association of Optometrists organizes the Optometric Leaders Forum (OLF), and brings together over 100 representatives from provincial associations and regulators, academics, and industry stakeholders to explore the challenges facing the profession, and to prepare for the future of optometry in Canada.

Massive data sets and algorithms in AI have the potential to improve patient care, streamline processes, and advance research.

A key strength of AI is prediction. Analysis of historical health data can help predict disease onset, progression, and outcomes, allowing eye care providers to intervene early, potentially preventing or mitigating issues.

Increased predictive ability can reduce uncertainty in all aspects of eye care and practice management, but as powerful as it is, AI can't replace the practitioner.

Effective use of AI can assist with efficient booking, triaging, and records management, reducing administrative burdens and freeing up staff for handson tasks and the personalized care patients expect.

When it comes to clinical applications, the potential of AI to transform eye care is even more impressive. We frequently refer to the eyes as "the windows to overall health" and this idea is even more relevant when applied to AI's capability of assessing and parsing data.

We see this in new areas of research, like oculomics, which examines biomarkers in ocular imaging to provide further insights into systemic diseases.



As this body of knowledge grows, so does the potential for developing tailored and data-driven approaches to diagnosis, treatment, and prevention of disease.

Along with the promise of AI come potential risks that demand careful consideration, especially in the context of health care. One critical concern is data security, as sensitive patient information requires robust measures to safeguard against unauthorized access and breaches.

Additionally, the risk of bias in AI algorithms poses challenges, particularly if the training data is not diverse, potentially leading to inaccuracies or disparities in diagnosis and treatment recommendations across different demographic groups.

Addressing issues of liability and accountability demands the simultaneous development of clear regulations, standards, ethical guidelines, and legal frameworks. These measures are essential to ensure responsible and equitable practices while fostering trust between patients and practitioners.

Supporting the responsible and effective application of AI can benefit both patients and practitioners by expanding access to care, facilitating collaboration, and enhancing diagnostic capabilities. When applied prudently, AI tools can ensure we provide better preventive care and treatment options and improve operational efficiency in our practices.

Al and technology are not a panacea, nor are humans infallible, however, when these elements converge, their combined strengths have vast potential.

Approaching AI as a complement to human expertise, rather than a replacement, can open our eyes to unexplored possibilities.



Adapting 'All the Light We Cannot See' for TV, and the Blind

Sutton and Ruffalo in a scene from the show. Sutton, who is from a small town in Wales, had starred in a campaign for a British charity before the show, but had no other acting experience.

PHOTO: ATSUSHI NISHIJIMA / NETFLIX

IMOGEN WEST-KNIGHTS, THE NEW YORK TIMES

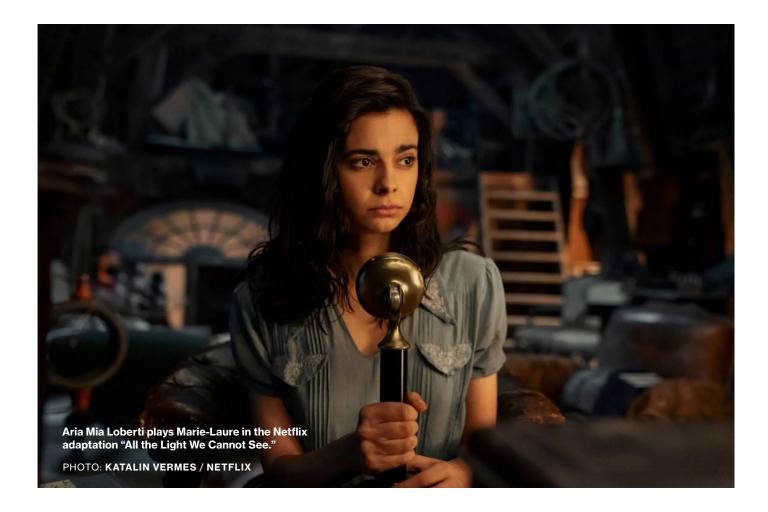
In a new Netflix mini-series, the two actresses playing the Pulitzer Prize-winning novel's protagonist, are blind, just like the character.

n a set on the outskirts of Budapest, as the crew reset cameras for the next take, Nell Sutton, 7, sat up in bed and asked her director, Shawn Levy, a question: "How will you make it look like night?"

Levy explained that the blue lights, set up around the room, would convey nighttime onscreen. Sutton was satisfied, and settled back into position, headphones on, to start a scene in which her character, Marie-Laure, is listening to the radio way past her bedtime. Her father, played by Mark Ruffalo, comes in and catches her. She tells him that she is learning about the magic of radio waves. "The most important light is the light you cannot see," she says.

Sutton, cast as the young Marie-Laure in "All the Light We Cannot See," Netflix's four-episode adaptation of Anthony Doerr's Pulitzer Prize-winning novel, is blind. The actress playing the character 10 years later, Aria Mia Loberti, is also blind.

In some ways the set, which took over a site next to an abandoned brewery last year for a few weeks over the summer, seemed like any other: People with walkie-talkies strode past equipment and craft services. But this production was the first time that



blind lead characters in a major television show were being played by actors who were themselves blind, and the attention that went into accommodating those actors, and making the show as true as possible to the experiences of people who are blind, was significant.

"All the Light We Cannot See" is set in occupied France during World War II and follows Marie-Laure, an amateur radio enthusiast and the daughter of a master locksmith at Paris's Museum of Natural History, and Werner (Louis Hofmann), a young German radio engineer who is drafted into a Nazi Wehrmacht squad to trace a radio signal that is broadcasting resistance messages. Marie-Laure is behind the signal, which she sends from Saint-Malo, a town on the northern coast of France, where she and her father moved while Paris was occupied.

The book's title refers to radio signals, and its protagonist's sightlessness, but also to moral blindness, Doerr said in an interview on set. "In many ways, Marie-Laure is a much more capable-sighted character than Werner for much of the book," he added.

The adaptation was directed and produced by Levy ("Stranger Things"), and co-produced by Dan Levine ("Arrival.") When the book came out in 2014, the producer Scott Rudin snapped up the adaptation rights to develop a feature film. Years later, when Levy learned that Rudin intended to let the rights lapse, he approached Doerr and proposed making a limited TV series instead. "That was much more exciting to me," Doerr said. "The novel is like 500 pages; it would be hard to go for 120 minutes."

Levy said that he and Levine agreed early on that Marie-Laure, both as a child and as an adult, should be played by blind actors. It was a risk for several reasons, Levine said, not least because studios like to cast big names in lead roles. The show has big names – Ruffalo as Marie-Laure's father, and Hugh Laurie as her uncle, Etienne – but the actors playing Marie-Laure would have to be unknowns.

The bigger issue was how to find them, since there are very few working blind actors. The producers and the casting directors did a global, open casting call, contacting schools and communities for the blind. "I thought, once we go down this road, we can't go back," Levine said. "We couldn't say, 'Well, we can't find anyone."

First, they cast Sutton, who was from a small town in Wales and who had starred in a campaign for a British charity, but had no other acting experience. Finding the older Marie-Laure took more time, and



the production team saw hundreds of auditions before a tape from Loberti, a Ph.D. student at Penn State University who had no acting experience at all.

The production's secret weapon, Levy said, was their blindness consultant, Joe Strechay. Strechay has been legally blind since he was 19, and described himself in an interview in his trailer as now being "totally blind." He previously worked with Netflix on the "Daredevil" series, and with Steven Knight, the writer of "All the Light," on the Apple TV+ series "See." "Having a lead character played by a person who's legally blind, this is what we've been working for for a long time," Strechay said.

Strechay consulted on all of the adjustments the production made to the set, including adding tactile marks to the floor that Loberti and Sutton could feel to establish their positioning, giving the actors time on set ahead of shooting to acclimate, and writing the series title in Braille on the directors' chairs and trailers. He was also involved in a directorial capacity. Strechay watched all of the rushes with his seeing assistant, Cara Lee Hrdlitschka, who described the scenes to him in minute detail so that he could give feedback on how Marie-Laure's blindness was being conveyed onscreen. "If someone who's blind or low-vision does something over and over again, it becomes easy," Strechay said. "So if it's supposed to be them arriving in a place they've never been before, we look at all those little movements to make sure they're accurate for that moment, for that character, in the story."

This led to frequent alterations, including to a scene in which Daniel teaches young Marie-Laure how to use a cane while walking down a busy street. Levine thought Daniel ought to be standing next to the curb, for Marie-Laure's safety, but on set Strechay corrected him. Daniel would want it the other way around, he said, so Marie-Laure could



The director Shawn Levy, right, approached Anthony Doerr, left, to adapt Doerr's 2014 Pulitzer Prize-winning novel into a limited series.

PHOTO: CHLOE ELLINGSON FOR THE NEW YORK TIMES

orient herself by the sound of the traffic and feel the curb with her cane.

These details mattered to Strechay, he said, because he has been generally unimpressed by media representations of blind people. Ruffalo played a blind person in the 2008 film "Blindness," and remembered mentioning this to Strechay when they first met. "He said, 'Oh yeah, I saw that. Nice try," Ruffalo said in an interview between takes.

Strechay has also helped the sighted actors understand how to interact with a blind person respectfully. In the scene in which Marie-Laure listens to late-night radio, Ruffalo, as Daniel, removed a pair of headphones from Sutton's ears. Because of the headphones, she couldn't hear Ruffalo when he entered the room.

"I know not to startle her, to just give her a little touch to tell her I'm there," he said, adding that onscreen, Daniel alerting Marie-Laure to his presence this way is also more authentic to the relationship between a blind child and her father. "It was important to me that we approach it this way," Levy said, not only because it seemed right, but because it ultimately made for a better show.

Working on this production has made the producers think differently about the primacy of sight in their work. One of the novel's strengths is how it immerses the reader in Marie-Laure's experience of the world: through smell, sound



Joe Strechay worked as the blindness consultant on set, helping to make it accessible to the blind actors.

PHOTO: ATSUSHI NISHIJIMA / NETFLIX

and touch. TV is a visual medium, but there are ways it can bring those other senses to the fore.

"It's so easy as a director to get image obsessed, shot by shot," Levy said. "And there's still that, because this is ultimately a television series that people will watch. Creating beautiful images is important to me, but my awareness of the tools that I have as a director is more 360."

He gave the example of the objects Marie-Laure has on her bedroom windowsill. "They wouldn't be items chosen for prettiness, they'd be chosen for the sound they make in a breeze, or the texture against the fingertips," Levy said. In several episodes, shots of Marie-Laure focus on her feet – walking over broken glass, navigating the streets of Saint-Malo with her cane – and so heightening the viewer's sense of how she perceives the world through senses other than sight.

Strechay said he hoped Sutton's and Loberti's performances would open the door for more blind actors. Sutton shared this hope, she said in an interview on set, adding that she was excited for other blind children to watch the series.

"Sometimes I say your gift is your blindness," she said. "And I say, even if you're blind, you can still do anything."

Accessible Canada: Accessible World – A Different Coming Together



DR. JUTTA TREVIRANUS

n May 27 and 28, 2024, online and at Concordia University in Montreal, the Inclusive Design Research Centre will bring together a global community of people who care about accessibility to strategize how we can collectively address intractable barriers and co-create new opportunities.

There have been many conferences on topics of accessibility, but barriers and ways to exclude are emerging faster than we can find collective time to understand them and address them. We need more than conferences.

We want to grow a community of practice that extends globally and that authentically includes the people who feel the greatest impact of the decisions made. This challenge of accessibility and inclusion is a matter that defies national boundaries, and we believe that Canada is in a position, and therefore has a responsibility, to significantly advance the global agenda.

So, unlike a typical conference, we hope to:

- Engage you as members of our community of practice before the gathering, but especially after the gathering to put the plans into action and refine them through trial and error;
- Recognize the knowledge and skills we all bring, rather than focus on and reinforce existing expertise hierarchies;
- Not spend our limited time repeating the same persuasive arguments to an audience that has already been persuaded, but move from there to plan approaches;
- Not ask you to spend your time listening to a chosen few with little opportunity to engage, but provide opportunities for everyone to productively contribute;
- Not discuss challenges in pre-existing silos because the challenges are complex and entangled, but go deeper to address the fundamental underlying issues and connections;

PHOTO: ANDRE MARTIN

- Not spend our time selling successes, but also pay attention to lessons learned from mistakes and failure and speak candidly and honestly about what works and what doesn't;
- Not rigidly preplan an agenda, when the world could change dramatically between now and May 27th, but leave room to include emerging issues;
- Not choose topics based on popularity or existing resource distribution, but attend to the critical challenges that have been ignored and underresourced; and
- Remove financial and logistical barriers to participation in whatever way we can.

So that we can spend the time together planning, presentations will be available ahead of time, online. You can view the ones that interest you, at your own pace, when it is convenient for you.

During the two days, we will plan together to address several critical challenges in each of four themes. For each challenge we will plan a sustainable collaborative project. This work will continue after the event.

We welcome presentations that contribute to our four overarching themes:

- 1. Who and what are we missing? What are the gaps?
- 2. Inclusive decision-making (fairer research, democracy, evidence, measuring, and intelligence)
- Innovation in standards and policy, including standards for disruptive emerging systems
- Accessible and equitable communications (including accessible journalism and traumainformed communications)

We welcome a diversity of formats, including stories, performances, artwork, and songs. Contact us at acaw@ocadu.ca for a presentation guide.

We hope you will join this collective effort and help us mobilize globally.

Share your insights & lessons learned, and help build a more inclusive course forward at this international event where lived experience is expertise

Un Canada accessible **Un monde** accessible Accessible Canada Accessible World

Conference

Flipped model

 Presentations available ahead of conference

 Attendees as active participants in discussions May 27–28, 2024

Concordia University (Montreal) and online

Four streams

Who and what are we missing?

Inclusive decision-making

8

Innovation in standards and policy

Accessible and equitable communications



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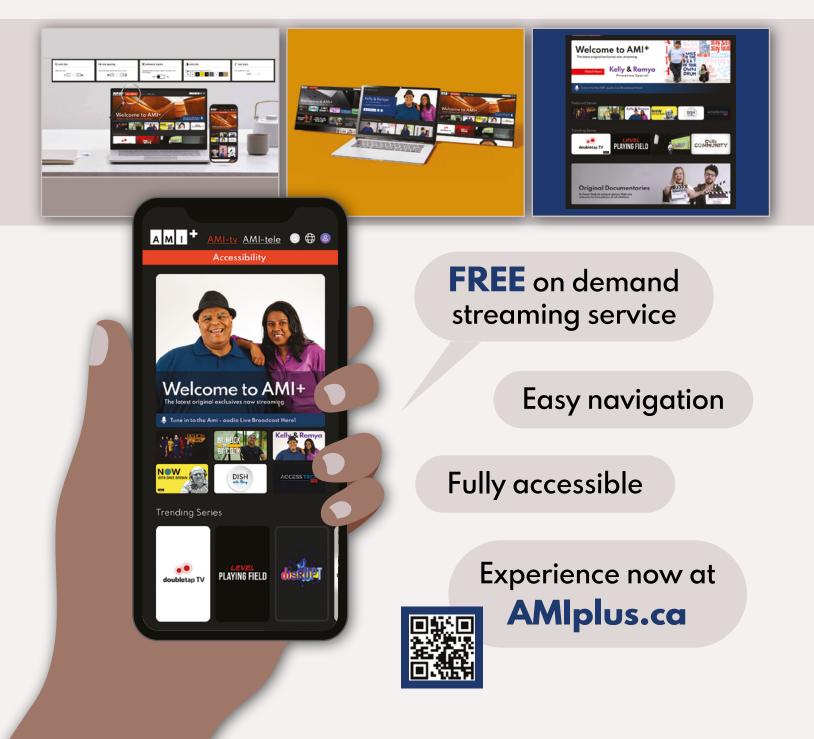
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AMI Unveils Free, Accessible AMI+



AMI has pulled back the curtain on AMI+, a free website offering a slick, modern look showcasing its one-of-a-kind, award-winning content.

With a streamlined layout, visitors to AMI+ can access AMI's stable of audio, television, and digital content created by and for the disability community. Additionally, visitors can utilize customizable accessibility settings for the blind and partially-sighted community AMI serves.

Months of rigorous testing and consultation with our audience and members of Fable – a diverse community of accessibility professionals, each identifying as having a disability – have resulted in an engaging, easy-to-use layout.

Placed at the very top of the site and on every page of AMI+, users can select Accessibility Preferences and choose from eight levels of contrast, plus change the line spacing and the font. Once these selections are made, the website will remember the settings. AMI+ is fully compatible with assistive technology, including screen readers and magnifiers, and Windows, Apple, and Android platforms and devices.

In addition to streaming original AMI-tv series and learning more about AMI podcasts, visitors can stream AMI-audio programming live, giving them access to NOW with Dave Brown, Kelly & Ramya, The Globe and Mail Today, Maclean's Magazine, Double Tap, and The Pulse as they are broadcast.



The cast of One More Time

AMI-tv programming available on AMI+ includes:

One More Time

From creator and stand-up comedian D.J. Demers and showrunner Jessie Gabe (*Workin' Moms*), *One More Time* is a workplace comedy about a fictionalized and heightened version of D.J. as the manager – who is hard of hearing – of a second-hand sporting goods store, and the team of employees he leads.

Push

Push is an unscripted series that takes audiences into the inner world of the "Wheelie Peeps," an unlikely group of friends and wheelchair users bonded by their shared experience of navigating life on wheels.

All-Access Comedy

All-Access Comedy is a standup special like no other, with comedians from the disability community coming together to celebrate their unique outlook on life for a packed audience of all abilities delivered in a venue with technology making it inclusive for all. Hosted by D.J. Demers, this one-hour special features performances by Courtney Gilmour, Tanyalee Davis, Ahren Belisle, and Ryan Lachance.



Mary Mammoliti, right, the host of *Dish with Mary*

Dish with Mary

Join Mary Mammoliti – a home cook and food blogger who is partially-sighted – as she travels across Canada, connecting with chefs to create mouth-watering recipes and to share tips and a laugh or two.

Mind Your Own Business

Hosted by Kevin Shaw and with the help of mentors, entrepreneurs in the disability community aim to take their businesses to the next level.

Visit AMI+ at AMIplus.ca today!

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

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

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.

Follow AMI on Facebook (@AccessibleMediaInc), X (@AccessibleMedia), Instagram (@accessiblemediainc), and TikTok (@accessiblemediainc).

national strategy to support eye health in Canada



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



Canadians living with vision loss



Canadians at risk of eye threatening conditions



0.0.0

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.

OUR KEY GOALS FOR BILL C-284:



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



Increasing investments for made-in-Canada research

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



Investments for eye health awareness, advocacy and support groups

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



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Donations through wills are often tax beneficial to your estate and loved ones while offering you the opportunity to empower the blind community. Your legacy can live on through technology training, preventive eye health advocacy, and innovative research.

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Lobbying to Bring Back Braille Menus

GERRY DEWAN, CTV NEWS LONDON

PHOTOS: GERRY DEWAN

Terry Hoddinott lost his vision to cancer when he was just three years old. He now runs a London, Ontario-based business that seeks to improve life for others with visual impairments.

He admits there are always hurdles to overcome, like the one he experienced during a recent visit to a Boston Pizza in Toronto when he asked for a braille menu.

"They said, 'Well, we have QR codes'," recounted Hoddinott. "I told them that doesn't work, it's not accessible and they said, 'We can stand here and read it to you' and I was flabbergasted."

Hoddinott said that option draws unwanted attention to people with visual impairments and makes the dining experience less pleasurable, "Independence is out the window when I have to stand there while you're reading the items to me. I have to ask the prices, flip back and forth."

He said it can be particularly awkward during a business lunch or in certain social situations, like a first date.

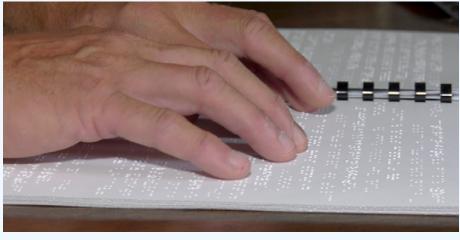
Hoddinott is supporting a change.org campaign designed to have all restaurants offer alternative menus with large print and braille in them. He says the large print is also helpful for seniors or those who don't do well in low-light situations.

Hoddinott said restaurants would only need two or three accessible menus on hand, "You keep them behind the desk. When you have somebody come in asking for them, you provide them at the table. Simple as that."

Hoddinot said Boston Pizza had braille menus up until about four



Terry Hoddinott, seen on August 25, 2023, is part of a lobbying effort to return Braille menus to restaurants that dropped them.



Terry Hoddinott reviewed a braille menu produced by his company on August 25, 2023.

years ago, but switched to using QR codes. The code links to an online menus and utilizes text-tovoice or text to braille technology, which links to a portable braille translation device.

Hoddinott said the technology is unreliable and not helpful for people who aren't tech savvy.

His business, Braille Masters, does custom braille transcriptions and printing. That does include providing braille menus to some clients, but he insists his campaign isn't designed to attract business. He would have no issues if another business landed the contract to provide braille menus. Just so long as they're available to customers, "It's one of those things that's a simple, easy fix and there's no reason for them not to do it."

Hoddinott has been reaching out to area MPPs to draw attention to the issue and says he and others are considering an Ontario Human Rights Commission Appeal.

People with Disabilities Will Soon Have to Pay Hamilton Bus Fare as New Program Slated for 2024

A new 'fare assist' program will instead provide low-income families a 30% discount

SAMANTHA BEATTIE, CBC NEWS

Every time Sharon Ruttan, who is a member of the Canadian Council of the Blind, boards a Hamilton bus, she's able to flash a card proving she has low vision in place of paying a fare.

The Canadian National Institute for the Blind (CNIB) card has guaranteed she can get around the city independently, regardless of her fixed income or low vision, Ruttan told councillors at a public works committee meeting Monday.

But come Jan. 1, changes to the HSR's subsidized fare programs will mean Ruttan and other residents who are blind, have low vision or use a mobility aid, such as a wheelchair or walker, can no longer use the voluntary pay program that's been in place since 2013.

As cost of living has "skyrocketed," Ruttan said, she doesn't have much money left at the end of the month to spend on transit, which she currently takes several times a week to volunteer, run errands or go to social activities.

"I get very emotional about this because it's not only going to affect me, but a lot of people both financially and emotionally," she said.

The city already received council's approval in July to move ahead with a new "fare assist" program that will offer low-income households a 30% discount.

Fare assist will replace both the voluntary pay program and affordable transit passes – monthly passes that could be purchased at a 50% discount for adults on a low or fixed income, says a staff report.

The city estimates about 500,000 bus trips a year are taken by people who don't pay a fare under the voluntary pay program and only 100 affordable transit passes are purchased a month.

Transit director Maureen Cosyn Heath told councillors Monday that more people will be eligible for fare assist than under the two other programs and it is more flexible, although many people living with disabilities will be losing the benefit of free transit.

"We understood and acknowledged these kinds of adaptations are difficult," said Cosyn Heath. "We knew



PHOTO: SAMANTHA BEATTIE

On Jan. 1, the City of Hamilton will end its voluntary pay program, which allowed people using mobility aids or who are blind to ride the bus without paying a fare.

it wouldn't be favourably received by everyone, but it was our best effort."

Staff estimate over 88,000 people in Hamilton will qualify for fare assist, which will be offered on a payas-you-go basis through Presto cards. If the estimated 10% of these people sign up, the city figures it will cost \$2.4 million a year, but will be paid for through the provincial gas tax.

Several delegates who live with disabilities told the public works committee they had learned of changes only this fall – months after an online public survey was conducted and the fare assist was already approved.

CNIB advocacy lead Bernard Akuoko said city staff didn't directly reach out to people with low vision and blindness to inform them of the survey and provide them with other ways to complete it other than online. As a result, many learned of the changes from bus drivers or the news.

"This is a vulnerable population," Akuoko said. "It's so important to get their real stories of what's going on."

Cosyn Heath said the city did a "solid job" involving community partners.

Councillors have the ability to open the fare assist program up to changes at the next council meeting.

Air Canada CEO Apologizes for Accessibility Barriers, Rolls Out New Measures

JOHN VENNAVALLY-RAO, CTV NATIONAL NEWS



People are shown at Pearson International Airport in Toronto on Friday, March 10, 2023. Air Canada CEO Michael Rousseau is apologizing for the airline's accessibility shortfalls and rolling out new measures to improve the travel experience for hundreds of thousands of passengers living with a disability.

PHOTO: NATHAN DENETTE / THE CANADIAN PRESS

Air Canada CEO Michael Rousseau has apologized for the airline's accessibility shortfalls and announced new measures to improve the travel experience for hundreds of thousands of passengers living with a disability.

Rousseau said the carrier will speed up a threeyear accessibility plan after a number of recent reports of passenger mistreatment, including an incident where a man with spastic cerebral palsy was forced to drag himself off of an airplane in Las Vegas due to a lack of assistance.

"Air Canada recognizes the challenges customers with disabilities encounter when they fly and accepts its responsibility to provide convenient and consistent service so that flying with us becomes easier. Sometimes we do not meet this commitment, for which we offer a sincere apology," the chief executive said in a release.

"We are committing to do better and demonstrating that commitment with concrete actions."

The measures range from establishing a customer accessibility director to consistently boarding passengers who request lift assistance first. Air Canada also aims to implement annual, recurrent training in accessibility – such as how

to use an eagle lift – for its 10,000-odd airport employees and include mobility aids in an app that can track baggage.

Heather Walkus, a member of the Canadian Council of the Blind and chairwoman of the Council of Canadians with Disabilities, said the problems go beyond a single airline, extending to gaps in the law – despite a regulatory overhaul in 2020 brought on by the Accessible Canada Act.

She cited the example of a rule requiring federally regulated companies to be involved in developing policies, programs and services – a "regulation you could drive a truck through."

"You could send the administrator down to Tim Hortons and talk to someone in a wheelchair and you've consulted with the disability community. It's a checkoff," she said. The group she heads was not contacted by Air Canada on its new accessibility blueprint, she added.

Air Canada executives sat down with Transport Minister Pablo Rodriguez and Kamal Khera, minister of diversity, inclusion and persons with disabilities, after a summons from Rodriguez last week prompted by several high-profile events involving passengers with disabilities. These included the Las Vegas incident with 50-yearold Rodney Hodgins, which triggered an investigation by the Canadian Transportation Agency. That event also prompted B.C. comedian Ryan Lachance, who has spastic quad cerebral palsy, to go public with his story of being dropped and injured by Air Canada staff while trying to exit a plane in Vancouver in May. He said crew had declined to use the lift he needs to leave his seat.

Rodriguez called the incidents "unacceptable." "We will be following up on the outcomes of this meeting, including before the busy holiday season, to ensure that all Canadians are treated with respect and dignity when they travel," he said in a post on X, formerly known as Twitter.

Craig Landry, Air Canada's chief operating officer, said the airline receives more than 700,000 requests for assistance from travelers with disabilities each year, or nearly 2,000 customers a day, underscoring the need for more reliable accessibility services.

"When customers are travelling with accessible needs, the expectation is that we're able to comply 100 per cent of the time," Landry said in a phone interview. "Any service failure is unacceptable."

The revamped accessibility plan, initially announced as a three-year process in June, will cost "in the millions of dollars," he said.

David Lepofsky, visiting research professor of disability rights at Western University's law faculty, said that as a blind person he "dreads" flying in Canada because of unreliable service.

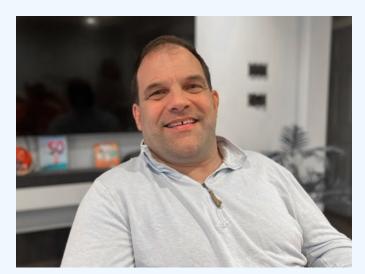
"The inconsistency with the quality of the ground assistance you get is appalling," he said.

"The problem is that we've got airlines that systemically are not ensuring that they respect that law and obey it, and a law enforcement regime that's fatally flawed."

Statistics Canada found that 63% of the 2.2 million people with disabilities who used federally regulated transportation in 2019 and 2020 faced a barrier.

Air Canada's new accessibility director, Kerianne Wilson, stressed that the airline will take greater pains to protect and track electric wheelchairs and other mobility aids when they're stored in the cargo hold.

"Their mobility aid, which we know is not luggage – it's an extension of their body, it's an essential part of their ability to travel and their independence – we know that providing that comfort will be so critical," she said in an interview.



Rodney Hodgins

PHOTO: ANDREW KURJATA / CBC



Ryan Lachance

PHOTO: CHARLES SCHRODT

Blind at 47, P.E.I. Woman Finds Freedom, Confidence in Social Life

Jennifer MacKinnon lost her sight in 2020 due to idiopathic intracranial hypertension

KRISTIN GARDINER, THE SALTWIRE NETWORK

PHOTOS: KRISTIN GARDINER



For some people, losing their sight later in life would seem like an end. For Jennifer MacKinnon, it has been a new beginning.

Since going blind at age 47, the Fredericton, P.E.I., woman has tried many new things and experienced a ton of "firsts."

These things include re-learning to cook, navigating a new washing machine, her first airplane ride – to Cuba, in mid-March, and the list goes on and on.

It hasn't been easy, but anything is possible with perseverance and a little help from your friends.

"You're still limited, and you're learning," said MacKinnon, now 49. "You're going from a full-sighted person to someone who can't see."

When she lost her sight, all MacKinnon could think of was one day returning to work as a nurse – a goal that, while it brought her hope, also brought her stress. "That's how I define myself," she said. "I really like nursing. I really do."

Her doctor recommended she find an outlet to channel her emotions, so she found a new way to spend her days in the form of yet another first.

Multiple times a week – sometimes even twice a day – you can find MacKinnon at Alberton's Iron Haven Gym, working the machines as much as laughing with her friends.

During a frustrating time in her life, MacKinnon said the gym was exactly what she needed for her mental health to return to form.

When she was a child, MacKinnon was diagnosed with idiopathic intracranial hypertension (IIH) – high blood pressure in her skull.

A shunt in her spine helped manage symptoms for much of her life – until, in October 2019, she

started experiencing headaches, felt unwell and had vision problems.

"I said, 'jeez, there's something not right," said MacKinnon. "And it just kept getting worse."

She went to the hospital and had a new shunt put in – this time in her head – and felt near-instant relief. It did not solve her sight issues, but the hope was, given time, it could improve.

It didn't.

A few months later, the shunt shifted out of place and her symptoms returned.

She went back to Halifax for a new shunt replacement; by then, though, her vision was gone.

"I can see shadows, I can see your outline and stuff, I can see a little thing of light," said MacKinnon. "Some colours are better, overcast days seem to be better. Bright lights, sometimes they're good."

Still, she is unable to read, unable to drive or return to work, and needs assistance to get around – whether it be a friend guiding her or using the cane she has been practicing with.

During her first few months without vision, MacKinnon felt lost.

"I just said, 'OK, I'm going give myself three months of pity party, and then I'm done," she said. "I just have to move on."

Losing her sight was rough enough; needing to ask for help made her situation tougher. With MacKinnon's nursing background, she's more comfortable giving help than receiving it.

"In the beginning, it was very hard. I'm not going to deny it," said MacKinnon.

Little things she'd previously taken for granted, like cooking, choosing outfits or washing dishes, were now challenges to navigate.

"When you're alone and you're thinking about it, and you think about what you had, you could get yourself pretty deep. I'm not in a bad predicament, because I have the social (life) and I have the will to go ... It was a friggin' eye opener – pardon the pun."

- Jennifer MacKinnon



From back left are Cheryl Hackett, Kim DesRoches, Mona Jeffery and MacKinnon, front.

She recalls one incident involving turned cheese.

"I made lasagna soup, and later on (my husband) went for a piece of cheese, he said, 'what cheese did you use?' I said, 'oh, that stuff on the top shelf on the left-hand-side," said MacKinnon. "He said, 'yeah, full of mould."

Now, MacKinnon boasts that she can cook nearly anything, use the washing machine on her own and even use the computer with the help of a screenreading program.

"It feels good," she said. "Maybe I'm arrogant in some ways because I know I can do it."

Despite how hard it was having to ask for help, MacKinnon now finds herself grateful for those at her side – both old friends and new.

One friend, Cheryl Hackett, has known MacKinnon since childhood. When Hackett thinks of MacKinnon, one word comes to mind: brave.

"A lot of her firsts, I did with her," she said. "Going out to a restaurant to eat. We get into the restaurant and I see her hands shaking and I just say 'look, we're just taking this one step at a time."

Her biggest support, though, comes from hitting the gym with Hackett, as well as fellow childhood friend Kim DesRoches and new friend Mona Jeffery, who she met through Hackett.

"The gym has been life-changing for Jennifer," said Hackett. "For all of us, but for her, really."

In particular, MacKinnon credits the newfound pastime for her growing confidence. In her earlier years, she used to be a tag-along, following the crowd. Now, she asserts herself, voices her own ideas and frequently makes her friends laugh at her quips.



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