

THE CANADIAN COUNCIL OF THE BLIND

WHITE CANE MAGAZINE MAY 2022

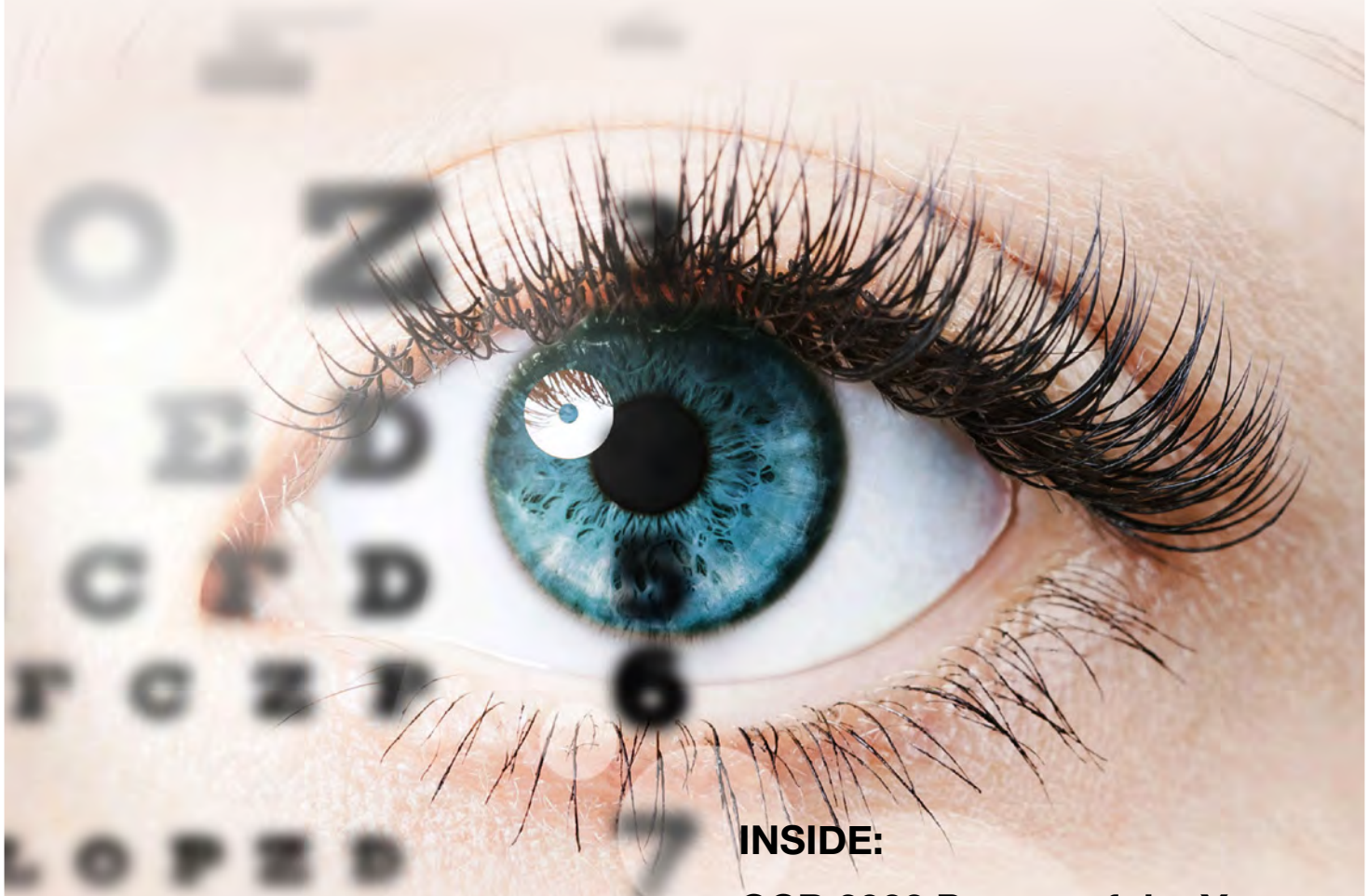
White Cane

The Voice of the Blind in Canada™

Magazine



Vision Health Month



INSIDE:

**CCB 2022 Person of the Year
Favourite Products and Apps
Experience Expo Is Back
Plans for a Sizzling Summer**



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We can give you 8 million reasons to sign our petition.

Pierre only needs 2.



Pierre lost his sight at the age of 32. Today, two of his grandsons have inherited the same eye disease that caused his blindness.

Over 8 million Canadians are living with eye diseases that can cause vision loss. 75% of those cases are preventable with early diagnosis and access to treatment.

The time to take action is now. Sign the petition to demand a National Vision Health Plan from our government.



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PRESIDENT'S MESSAGE



Photo by Andre Martin

Every May, Canada marks Vision Health Month – a time to reflect on just how important good vision is to our everyday lives. It's also an opportune time to raise awareness about eye health and the simple steps we can take to maintain it. This is especially essential since 75 percent of vision loss is preventable. Today, 1.2 million Canadians experience vision loss, and this number is expected to increase to 2 million by 2050. We're experiencing a crisis of preventable blindness. However, with appropriate awareness and care – including regular comprehensive eye exams, increasing vision care access for those who need it most, ongoing vision research, and equitable access to treatment – we can protect Canadians' eyesight and put a stop to this crisis.

This Vision Health Month, the Canadian Council of the Blind (CCB) has a full line-up of events planned. They kick off on Tuesday, May 3 with Hill Day, which marks the launch of a month-long federal government vision advocacy stakeholder initiative. Meetings with government officials will be held virtually, in Ottawa, and with MPs in their ridings across the country.

Our Vision Health Month Special Section with MediaPlanet appeared in the Toronto Star on Saturday, May 7, in The Hill Times on Monday, May 9, and digitally on Wednesday, May 11. This initiative aims to increase public awareness of vision health.

On Monday, May 16, the CCB will host our annual Vision Health Month Summit (presented both live in Ottawa and virtually), featuring a discussion on achieving the vision health community's push for a National Vision Health Strategy, a Vision Health Desk, and increased vision health research funding.

Our CCB Vision Health Month 2022 Gala Dinner (also presented both live in Ottawa and virtually) will take place on Tuesday, May 17. We're looking forward to presenting this year's White Cane Person of the Year and CCB President's Awards, and to welcoming our Keynote Speaker, Luna Bengio.

The CCB's Toronto Visionaries Chapter's Experience Expo Consumer Show will take place on Saturday, May 28 in Toronto. The Expo is an interactive, hands-on exhibition featuring dozens of exhibitors, products, and services related to living with vision loss. It's always a popular event for those with seeing disabilities along with their friends and families.

Directly following the Experience Expo Consumer Show, the CCB's Toronto Visionaries Chapter will host its annual Experience Expo Forum (presented both live and virtually). The Forum will feature a panel of experts discussing a patient's right to informed consent and full disclosure regarding treatment decisions.

We hope you will join us in celebrating Vision Health Month. Whether visually-impaired or sighted, the vision loss crisis affects us all – and we must continue to raise awareness and advocate for change to create a brighter future.

A handwritten signature in black ink, which appears to read "Jim Tokos". The signature is written in a cursive, flowing style.

Jim Tokos
National President, Canadian Council of the Blind

“We’re experiencing a crisis of preventable blindness.”

ABOUT THE CANADIAN COUNCIL OF THE BLIND



The Canadian Council of the Blind (CCB) was founded in 1944 by schools of the blind and returning blind Canadian war veterans and is recognized as the Voice of the Blind™ in Canada. The CCB is a membership-based not-for-profit that brings together Canadians who are living with vision loss – those who are blind, deaf-blind, and partially-sighted. In doing so, the CCB maintains a vibrant network of active members in 80 chapters across Canada. Each chapter is unique to its geographic area and engages in a variety of social, recreational, and community activities based on the interests of its local members.

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

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 to vision issues for 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 best in available medical treatments, research, and the fostering of patients' rights without limitation or discrimination. The CCB works with its vision partners Fighting Blindness Canada (FBC) and the CNIB to provide a united voice for people living with vision loss and to advocate for access to innovative treatments to prevent vision loss and restore sight. Together, we advocated to bring anti-VEGF medications to Canada in 2006, and, more recently, to gain access to two new medications to prevent blindness in AMD and diabetes-related vision loss in the past year. We've increased access to the first new glaucoma medication in

the last 20 years, which is now publicly funded in eight provinces, and achieved a positive recommendation of the Ontario Health Technology Advisory Committee (OHTAC) to recommend public funding of a minimally-invasive glaucoma surgery device. We also advocated for the first targeted gene therapy to restore sight for an inherited retinal disease.

Over the last number of years, the CCB has produced important reports on accessible technology and assistive devices. The CCB was quick to report “The Impact of the COVID-19 Pandemic on Canadians Who Are Blind, Deaf-Blind, and Partially-Sighted” in April 2020. Late that same year, and released in May of 2021, the CCB commissioned, and was joined by partners FBC, the Canadian Association of Optometrists, and the Canadian Ophthalmological Society, the study on “The Cost of Vision Loss in Canada,” seen as the most consequential report on vision loss since 2007.

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. We do 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 vision loss and blindness are preventable.

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

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

Thanking Our First Responders

The Canadian Council of the Blind (CCB) would like to thank all health care workers and their support staff for the remarkable work you’ve done throughout the pandemic. You are on the frontlines, battling the coronavirus, day in and day out. You have put your patients’ lives ahead of your own. Your service to your patients is saving countless lives and has enabled so many of us to return to living a somewhat normal life. You have been sensitive to the special needs of people living with vision loss and have thereby made our lives more tolerable and less lonely at this difficult time. Your dedication, commitment, and courage deserve our deepest gratitude and admiration.

In addition to health care workers, the CCB would also like to acknowledge and thank the many thousands of other frontline workers who have helped us weather the pandemic. To all firefighters, police officers, and other first responders; teachers; personal care workers; grocery store workers; store sales and check-out staff; utility workers; janitors; truck drivers and everyone doing our deliveries; food manufacturers and distributors; postal workers and utility workers; and the many other frontline workers who have helped provide us with essential items and services, we extend our gratitude and respect. Your selflessness has helped us through these difficult times.

In recognition of the efforts and sacrifices of health care and frontline workers, the CCB encourages everyone to get fully vaccinated (including having a booster shot where available), to wear a mask, to observe social distancing, and to follow all local and provincial guidelines and recommendations. If we all work together, we can minimize the worst aspects of the pandemic.

We hope that 2022 will be a better year for us all. Stay safe, and once again thank you for all that you do.

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

The 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.



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Editorial

Continued Marginalization Does Not Address the Vision Loss Community's Deficiencies, Both Socially and Economically



The month of May is Vision Health Month, which provides an opportunity to celebrate the successes of Canadians who are blind or vision-impaired, as well as to shed light on the challenges that many still face. It's also a fantastic time to raise awareness about eye health and ways to prevent vision loss.

Our research indicates that in Canada, there are an estimated 1.2 million people who are blind or vision-impaired, representing 3.2% of the population. In fact, more than 8 million Canadians are living with an eye disease that may lead to blindness. Since the most common eye diseases are age-related and since Canada's aging population continues to increase, the number of Canadians with vision loss is projected to increase to an estimated 2 million by the year 2050. At the same time, the cost of vision loss is estimated to increase from \$32.9 billion in 2019 to \$56 billion (in 2019 dollars) by 2050.

Although the vision-impaired community has made strong strides toward inclusion, unfortunately negative and often unconscious stereotypical attitudes remain among the sighted community about blind and visually-impaired persons. As a result, the blind and visually-impaired community is the most marginalized disabled group in this country, both socially and economically.

In my February editorial, I spoke of the importance of collaboration between organizations in order to address these inequalities – an idea the Canadian Council of the Blind (CCB) wholeheartedly supports. As an example, over the past year, the CCB, in partnership with the Alliance for Equality of Blind Canadians, BALANCE for Blind Adults, the CNIB, Fighting Blindness Canada, and OCAD University, conducted a user experience survey of the Assistive Devices Program administered by the Ontario Ministry of Health. The results of this important study have since been published, including its findings, conclusions, and recommendations. I encourage you to review the study.

This study highlights the fact that without access to the vital services or support systems necessary to learn independence and integrate with their sighted counterparts, many people who are blind or visually-impaired are isolated and barred from active and vibrant participation in their communities, and, indeed, the marketplace as well.

We know that one of the major voids within the blind and visually-impaired community is acquiring and training in assistive technology. Knowledge in this area can transform an environment of isolation and desparation into a productive, meaningful, and fulfilled life. The CCB is addressing this issue with our Get Together with Technology (GTT) program (see pages- to come), which provides computer literacy training as well as a space for individuals to support each other. This program is designed to enable blind and visually-impaired individuals to gain access to information and communication through computers and adaptive technology.

Through this program and others and along with a strong volunteer base, the CCB remains committed to working with all levels of government and virtually every sector of society to ensure that blind and visually-impaired persons share and participate equally in the bounty that Canada offers. It's in everyone's best interest that all Canadians can contribute positively to their community and country.

I encourage you to join us and show your support during Vision Health Month. Take advantage and participate in the events hosted by the CCB and other organizations and help us raise awareness of the issues being faced by our community.

A handwritten signature in black ink, appearing to read "Mike Potvin".

Mike Potvin
Editor, White Cane Magazine

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Luna Bengio Presented with the 2022 Person of the Year Award

The Canadian Council of the Blind is pleased to announce Luna Bengio as this year's White Cane Week Person of the Year. Bengio, a seasoned Canadian public service executive and accessibility expert, is a shining example of the type of dedicated advocate and service-oriented professional that the blind, deaf-blind, and partially-sighted community so desperately needs.

Bengio joined the Government of Canada's Office of Public Service Accessibility when it was established in August of 2018, where she acted as the Principal Advisor to the Deputy Minister until her retirement in June of 2021. From policy to projects, Bengio tackled a range of accessibility issues. "I've done a lot of work to foster a public service culture that's more inclusive and that sees people with disabilities as people first – and as people who can bring a source of talent to the public service," says Bengio. "The idea is to improve opportunities for people to join the public service with the right conditions – that is to say, with access to any supports or accommodations that they may require to be successful in their jobs."

Bengio's work has also focused heavily on improving access to information and communications technology, which is essential in enabling people living with vision loss to access the world – including the workplace.

Since July of 2021, Bengio has been supporting the Office of Public Service Accessibility and Shared Services Canada's Accessibility, Accommodation and Adaptive Computer Technology Program. There, she provides strategic advice on a range of accessibility and inclusion issues, such as workplace adjustments, information and communications technologies, and culture change. She also contributes to several key initiatives, including the review of policies from an accessibility perspective and the development of the Government of Canada Workplace Accessibility Passport.

"The Workplace Accessibility Passport follows employees through their career in the public service," says Bengio, adding that its goal is to help people identify barriers they experience in the workplace and corresponding solutions. "It was created in direct response to issues raised by employees with disabilities."

Aside from supporting government employees with workplace accommodations and acting as a champion in advancing digital accessibility within the government, Bengio has enjoyed an illustrious career in the federal public service since 1990, with a broad range of roles and responsibilities. "I've worked in planning, access to information, IT, policy, programs, infectious disease control, and financial and human resources management," says Bengio. "I've had a great series of opportunities to learn and work with some interesting people, and also to give back to Canada some of what it has given me, which is opportunity."



Dr. Deborah Gold and the Team at BALANCE for Blind Adults Awarded the 2022 President's Award

This year we mark the bestowal of the 11th Annual President's Award, which is given to an individual, organization, or entity that in their work or service with or for the blind, deaf-blind, and partially-sighted has made a real difference in improving the quality of life of the members of this community. One of this year's President's Award recipients is the team at BALANCE for Blind Adults and its Executive Director of six years, Dr. Deborah Gold.

Since first opening its doors in Toronto in 1986, BALANCE has taken a fresh approach to supporting people who

are blind or partially-sighted in living independently and engaging with their communities. BALANCE began as a community living environment for young adults and over the years has maintained a focus on fostering self-reliance and facilitating clients' connection to community resources. In its 30-plus year history, BALANCE has expanded its offerings thanks to funding from the Government of Ontario, grants, and donations. Its unique services now include community engagement, counselling, occupational therapy, orientation and mobility training, and technology training. "One thing that

has remained constant and that really continues to be difference-making is that at BALANCE, we support the whole person,” says Dr. Gold.

BALANCE’s clients are amongst the most vulnerable within the vision-impaired community. Almost half (48 percent) of its clients last year had no functional vision, as compared to 10 percent of people with sight loss in Canada and worldwide. “Our clients often have additional challenges, too – disabilities, other physical and mental health conditions, social isolation, speaking English as a second language, and limited financial means,” says Dr. Gold.

BALANCE’s distinctive service offerings are a reflection of the diverse community it serves and its commitment to that community and its members’ complex needs. BALANCE’s occupational therapy, for example, is unique in Canada, and was introduced to support clients faced with challenges related to daily living, communications, ableism, poverty, and more. BALANCE has also been making progressively notable strides with its mental health supports, and now includes a specialist with lived experience amongst its staff along with confidential group and individualized counselling. BALANCE’s holistic, all-encompassing services and supports are truly innovative.

“We make sure that our values – inclusion, respect, empathy, trust, and independence – are incorporated into everything we do,” says Dr. Gold. “We have an amazing team that I’m so proud of. They really put the clients first. We also have a strong volunteer program.”

Dr. Gold herself is an expert in engaging partners and collaborators, developing and leading staff teams, coaching staff and volunteers, and managing multiple strategic projects. Before joining BALANCE, she worked for 16 years at the CNIB in progressively advanced roles, most recently as its National Director of Research and Program Development.

Fuelled by this dedicated team and driven by Dr. Gold’s visionary leadership, BALANCE continually innovates and evolves. In response to the pandemic, the organization immediately pivoted to virtual learning for its technology training program and mental health support groups, and launched a tele-support service to connect with isolated clients. By the fall of 2020, BALANCE had dramatically increased the number of online activities, events, and groups offered to its clients, and had established partnerships with a theatre company, musician, the Royal Ontario Museum, and others to provide engaging online programming for the BALANCE community. BALANCE also launched its monthly Living Blind Podcast in late 2020, as well as its Assistive Technology Apprenticeship Program. “There’s a shortage of assistive tech instructors

in the field, so we decided to start a ‘grow-your-own’ approach,” says Dr. Gold. “This program increases employment opportunities for people with sight loss while also fulfilling our need to teach others. It’s a win-win-win – for BALANCE, for the community, and for people with sight loss.”



Throughout the pandemic, BALANCE also worked to address issues of social isolation and food insecurity, and launched a comprehensive vaccine education and engagement program.

The team at BALANCE continues to push boundaries with its programming, innovation, client supports, partnerships, and reach. “Our staff, Board, and volunteer team are the reason we can achieve these new heights each year, and we’re so very proud to receive this recognition of our work,” says Dr. Gold.

In bestowing the 2022 President’s Award, the Canadian Council of the Blind commends Dr. Gold and the team at BALANCE, and offers our continuing support to their vision, inspiration, and commitment to supporting independence and wellness within the vision loss community.



Glaucoma Care in Canada: National Survey

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

A SURVEY OF 150 CANADIANS WITH GLAUCOMA REVEALS:

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

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



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

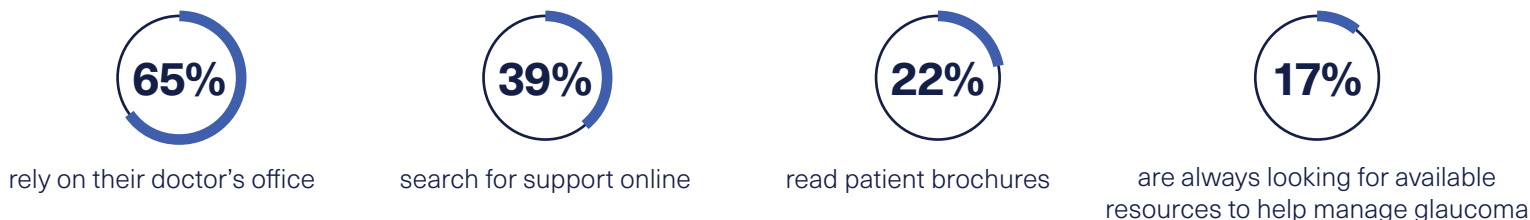
22% of glaucoma patients experienced some **VISION LOSS** before being diagnosed

Current therapeutic treatments used for glaucoma:



9% of respondents use other treatments while **1%** don't know what treatment they use

Accessing resources and information on glaucoma:



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

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

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

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

Survey Methodology:

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

References:

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

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PRESIDENT'S AWARD RECIPIENT KEITH GORDON

One of this year's President's Award recipients is Dr. Keith Gordon, the Senior Research Officer of the Canadian Council of the Blind (CCB). Dr. Gordon was the principal investigator of four CCB studies: "The Impact of the COVID-19 Pandemic on Canadians Who Are Blind, Deaf-Blind, and Partially-Sighted" (April 2020); "The Cost of Vision Loss and Blindness in Canada" (March 2021); "The Impact of the COVID-19 Pandemic on Eye Health in Canada" (September 2021); and "Reforming Ontario's Assistive Devices Program" (February 2022). He also authored the CCB report "A Needs Report on Accessible Technology" (November 2019).

"I think what I've been able to do is conduct research that can create the evidence base that can be used for advocacy for people living with vision loss," says Dr. Gordon. Indeed, Dr. Gordon's work has created a strong backbone of research and data to support advocacy efforts. As he notes, having solid data at hand is essential, particularly when engaging with government agencies.

The President's Award acknowledges those who in their work or service with or for the blind, deaf-blind, and partially-sighted have made a real difference in improving the quality of life of the members of this community. Dr. Gordon's contributions and commitment make him well-deserving of the award. His leadership has enabled the CCB to create high-impact reports and to share powerful findings with key decision-makers.

Dr. Gordon's work in the field extends back many years. He's past Vice President of Research at the CNIB, where he worked from 2007 to 2017, directing all research activities. Prior to that, he spent over 30 years in the ophthalmic pharmaceutical and device industry, where he was responsible for a wide range of research and scientific activities. Dr. Gordon is past Research Director of Blind and Low Vision New Zealand and is currently Chair of the Board of BALANCE for Blind Adults and Chair of the Board of the international organization Retina Action. He's also an adjunct professor in the Department of Ophthalmology and Vision Sciences at the University of Toronto and an Honorary Teaching Fellow in the School of Optometry and Vision Science at the University of Auckland in Auckland, New Zealand.



"I'm proud of the fact that I've been able to utilize research to make a difference in people's lives," says Dr. Gordon. "It's very special for me to be given this award by the CCB, an organization with wonderful people with whom I've been privileged to work for the past several years."

Dr. Keith Gordon's commitment to advancing advocacy for the vision loss community is commendable, and the CCB offers our ongoing support to his vision, leadership, and dedication.

An Update on the Get Together with Technology Program

By Corry Stuive

It was March of 2020 when we as Canadians were hit with the news and reality of the COVID pandemic. This necessitated a change to the way we at the Canadian Council of the Blind (CCB) needed to deliver our Get Together with Technology (GTT) program. I'm proud to say that the CCB was one of the first organizations to utilize and implement the Zoom platform as an alternate and viable delivery tool. Several "open tech chats" have continued weekly for the past 24 months. In addition to the open chats, we've enjoyed many presentations as well as topic-specific calls dealing with various accessible hardware, software, and other related accessible topic matter. Smart phones, tablets, and smart speakers are just a few of the products that have been subject matter for our hundreds of calls. Together, we have taught, learned, and supported each other in the ever-changing world of technology. This is the power of peer support and the strength of the CCB: learning from each other, with each other.

Recently, we've shifted the focus of the GTT program slightly to include a smaller group learning environment, based on input and feedback from prospective participants. It was felt that the slightly smaller group format would afford participants an enhanced learning opportunity, via the chance to drill down on one's specific and unique needs, questions, and concerns. This form of instruction has proven to be extremely successful, and we look forward to enhancing the program in the months to come. Again, based on participant input, there's no shortage of topic matter and of course your ideas are always encouraged and welcome.

We plan to continue with the virtual Zoom call meetings until at least September of this year. As we move forward, and it does appear that some of the pressures of COVID may soon be behind us, we would appreciate your input on how you feel the GTT program should move forward in the fall. Do you want to go back to face-to-face meetings in various communities that may have had them before? Do you want a more locally-focused group in a region where there's not currently a group? Would you like to see a hybrid situation, with some Zoom and some in-person sessions? Please write to us and tell us what you think at gttprogram@gmail.com. Any and all feedback is welcome.

In closing, we wish to thank all of you for supporting the program over the years. The CCB GTT is now into its 10th year of operation and its success is directly attributable to you, the program participants. Thanks for your feedback, knowledge, support, and overall program involvement. We look forward to the next 10 years.



Q&A with Kim Kilpatrick, Co-Founder of the Get Together with Technology Program



*Kim showing love to her favourite guide dog Tulia who recently passed.
Photo by Joan Anderson Photography*

We sat down with Kim Kilpatrick, one of the original founders of the Get Together with Technology program, to get her take on how technology enhances the lives of those living with vision loss and what changes she has found most valuable.

Since you started the Get Together with Technology (GTT) program, much has changed. What strikes you the most?

When a friend and I started the GTT program in Ottawa 10 years ago, I never would have dreamed where the program would go from such a humble beginning. Similarly, I wouldn't have dreamed of the advances in technologies of all kinds to make living life as someone who is blind or who has low vision so much improved. This is possibly the best time in history to be blind.

How has technology changed your life over the years?

Information is much more accessible and available to me and others living with vision loss, whether it's the vast amounts of books provided by the Centre for Equitable

Library Access (CELA), the National Network for Equitable Library Service (NNELS), Kindle, iBooks, Audible, and more, or the accessibility of news and information through many mainstream apps and websites. The ability to scan and read documents, products, and information through apps such as Voice Dream Scanner, Seeing AI, and others is another incredible technological innovation that has enhanced my life. We also now have excellent video call support through apps like Be My Eyes, Aira, and FaceTime. Accessible, out-of-the-box technologies are now provided by Apple, Microsoft, Samsung, Google, Amazon, and others. Who would have believed that I could set up my own systems independently and customize them as I wish without buying expensive additional technology to do so? I'm never without my electronic braille device and the advances in lower-cost and multi-line braille are fast improving. I'm amazed that today I can read anything on my phone or computer in braille. Smart speakers have also changed our lives and made accomplishing tasks such as setting timers and alarms, listening to music and podcasts, asking for information, sending texts, and more so much easier for many of us. Ride-sharing, taxi, transit, and GPS apps and systems have allowed us to more easily navigate our cities and to travel independently. Online shopping apps have helped us to shop more independently as well. Who would have believed that we'd be able to keep going through COVID with the extensive use of Zoom to connect us all across Canada?

What has stayed the same for you over the past decade?

Although technology is fascinating and important to me, we must remember that low-tech items such as locator dots, braille, large print labels, white canes, and guide dogs are equally valuable tools in our toolbox.

What has been the most rewarding part of co-founding GTT?

Most important of all, to me, has been the personal connections with Canadians who are blind, deaf-blind, and low-vision from across our country.

Our Favourite Innovative Products and Apps for People with Vision Loss

By Kim Kilpatrick and Corry Stuiwe

As staff members of the Canadian Council of the Blind's Get Together with Technology team, we're pleased to inform you about some of the products and apps that have made the most difference in the lives of those who are blind and partially-sighted in Canada. While it was a challenge to narrow the list down and decide which items, features, and apps to include in this article, we've listed many that are now playing a key role in our lives.

It's great to see that accessibility features are implemented into these products from the outset, rather than us having to lobby for them and have them added later. We're also delighted that so much more is accessible to us without an added financial burden for specialized equipment or training, which was a common reality in the early days of assistive tech.

Without further ado, here are our favourite products and apps for those living with vision loss:

PRODUCTS



iPhones, iPads, and Apple watches

Apple was the first of the large mainstream technology companies to make its products available with accessibility built in. This meant that anyone could turn on VoiceOver (Apple's built-in screen reader) or the low-vision features while setting up the device and continue to use them. This was a very empowering experience. We're encouraged that other mainstream technology companies have followed suit, including Android devices of all types, Microsoft computers, and Kindle tablets.



Smart speakers and devices

Smart assistants came along in 2011 with the launch of Apple's Siri voice assistant, which is still present on Apple products today. Soon afterwards, more smart speakers and assistants entered the market with Amazon's Alexa, Google Home and Google Assistant, and more. These assistants mean that people can use their voices to do a myriad of things very conveniently, such as setting timers, alarms, and reminders; looking up information; playing music, books, and videos; doing online shopping; and accessing all sorts of other online content. With a smart speaker, we're all equal. It's a product not specifically designed for low- or no-vision users and thus pricing, availability, and future content development are all working in our favour.



Entertainment accessibility products

The accessibility of streaming audio and video services and apps has increased the amount of content we can access and enjoy. Described video programming is becoming more of a reality and again producing content with it included, rather than adding it later, is a welcome plus. Companies like Netflix and Amazon now include described video (DV) on all content produced in-house. Many of the streaming services include access to DV and are accessible on devices like phones and tablets. Some accessible set-top boxes have made things much more accessible for Canadians with vision loss as well.



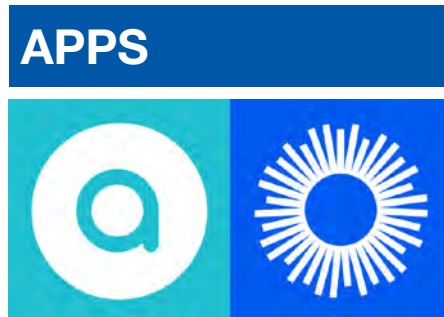
Health and fitness monitoring devices

The advances in technologies that help us monitor various components of our personal health, independently, are simply astounding. Systems with sensors to better monitor blood sugar levels, oxygen levels, heart rate, and more are either available now or will be shortly. We also can now use many types of blood pressure machines, thermometers, and other fitness trackers to help with our health.



Electronic braille readers and writers

The advances in devices for reading and writing in electronic braille are amazing and progressing as well. Cost in regards to braille production and access have been somewhat of a barrier in the past, however several companies are working on lower-cost technologies for producing electronic braille devices that will show a braille user what's on their phone or computer screen. We've now seen the first multi-line braille display as well as other companies working on tactile graphics using these types of technologies. The future is bright for braille.



Aira and Be My Eyes

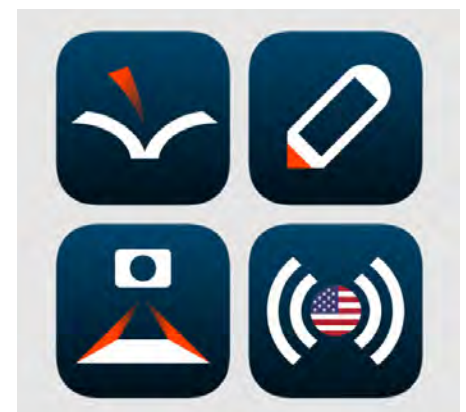
These apps allow you to make a video call to a sighted person and get information, help, or directions. In essence, they are seeing what the user is not, via the camera on a user's smart phone. Apple's FaceTime is similar and can be used with friends and family. Be My Eyes is a free service that connects you to volunteers. Aira is a paid subscription service that connects you to paid and bonded agents who are fully-trained and vetted to assist you. Aira has also made its service available at no

charge to the end user for such tasks as voting on election day, COVID testing, and employment searches, for which we're truly thankful.



Seeing AI by Microsoft

This is a free app that allows you to do so much: scan bar codes of products to determine what product you're holding, read your printed mail, scan documents, and so much more. It can tell if the lights are on in a room, identify currency, and read handwritten notes. Other similar apps are also around, including EnVision and Supersense, so we have many apps to help us with everyday tasks that previously were incredibly difficult.



Voice Dream Suite

The Voice Dream Suite is a bundle of apps from Voice Dream LLC. It includes Voice Dream Reader (an app that allows you to read talking books, articles, and PDFs, to play MP3 files, and much more), Voice Dream Writer (a word processor), and Voice Dream Scanner (which allows you to scan and save documents). This is one of the most useful bundles of apps.



Instacart

Over these past two years of COVID, many of us have turned to online shopping for groceries and other products. For those of us in the blind community, this has been extremely helpful. Shopping is always an adventure and shopping apps give us more independence knowing which products are available and ordering what we need when we need it. Many stores are now offering their own apps and delivery options, so choice is now also becoming more available. The Instacart app is just one of the many grocery delivery services available.



DoorDash, Uber Eats, and Skip the Dishes

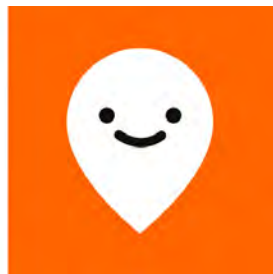
Restaurant delivery is nothing new, however these apps and the built-in accessible menus have made the process somewhat easier for folks with no or low vision. Picking up orders can often be difficult or challenging, so the option of using delivery apps is extremely helpful.



Audible

Audible is a source or library filled with audio books you can buy. It has made its apps for iOS and Android very accessible. Audible's website is extremely accessible as well.

TRANSIT APPS



Transit apps such as Transit, Moovit, and other local apps have helped us to check transit schedules, monitor the stops when we're on board, help us plan routes, facilitate the disembarking process, and more. This is essential for those of us using public transit on a regular basis and makes planning and riding the bus, streetcar, or train so much easier.



Google Street View

The Google Street View app is particularly useful for low-vision users. Having a look around at a streetscape before you get there can be extremely helpful. Locating specific addresses or landmarks can help tremendously, especially in unfamiliar locations.

The past 10 years have brought exciting change that has greatly enhanced the lives of those of us living with vision loss. We can't wait to find out what new accessible innovations will arrive within the next 10 years.



Proceeding Without Us

*By Jutta Treviranus,
Professor and Director, Inclusive Design Centre*

With the passing of the Accessible Canada Act, the federal government made a commitment to Minister Qualtrough's assertion, "Nothing without us, because everything is about us." This is vital when decisions are made that will have an impact on the lives of persons with disabilities.

One area where decisions are made at a rapid pace is technology systems. It doesn't need to be said that technology is changing constantly, often in unexpected ways. All government services and interactions involve using technology, from filing taxes, to applying for daycare, to receiving a pension, to applying for citizenship, or registering for a vote. Our government runs on a technology system.

Technology decisions, especially decisions involving digital technology, cannot be retrofit. Once the system is adopted, the impact of the decision propagates. The system morphs — it makes connections that cannot be easily reversed or pulled back. This means that decisions about technology systems must have the participation of the disability community from the start.

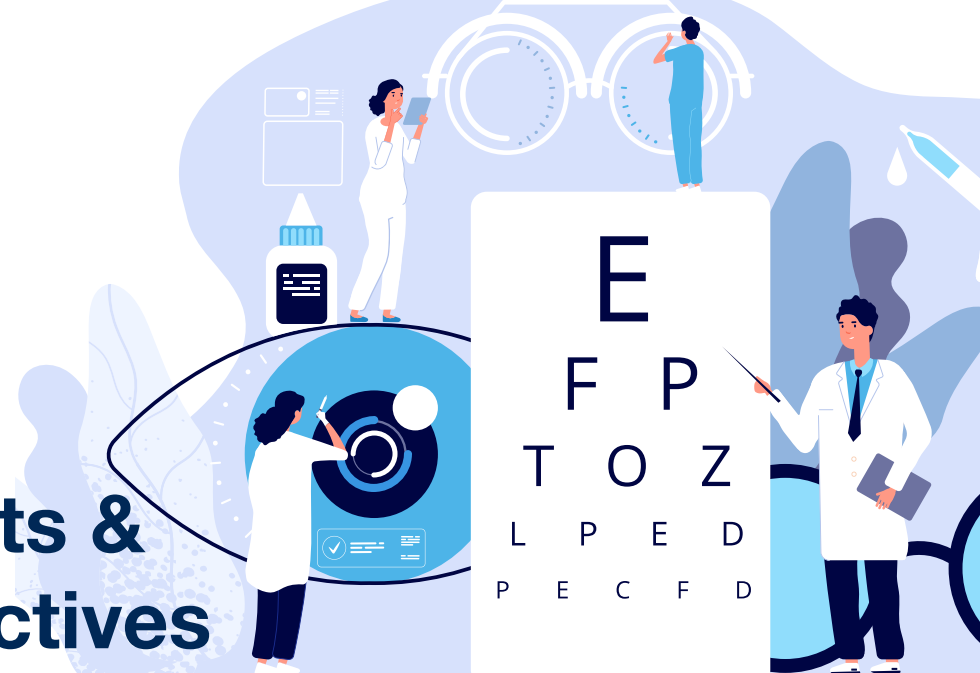
To be able to participate in decisions in a meaningful way requires an understanding of the implications of decisions and knowledge about how to achieve greater inclusion. Unfortunately, there are many systemic barriers to this for the disability community. The technology field lacks knowledge about how to design emerging technology systems accessibly. General education in technology systems has many accessibility barriers. Markets make it difficult to afford digital systems to gain digital literacy, and there's a dearth of digital systems that are accessible. To reach a meaningful level of participation in the decisions will require a large, concerted effort.

One small program that was supporting projects to address these barriers was the Accessible Technology Program of the Ministry of Innovation, Science and Economic Development (ISED). The investment was comparatively tiny given the huge task, the number of people affected, and the relative investment in technology innovation in other areas. Unfortunately, even this tiny investment has been sunset, awaiting the next budget and a new application

process. This means that all the projects that have gained momentum must stop and wait while irreversible technical decisions are being made. For the disability community, this is the equivalent of saying we're going to stop all national security efforts and safety monitoring, including all efforts to advance our understanding of security and risk, and lay off all the staff until the next budget and an application process.

To meaningfully keep the commitment to "nothing without us," we need to make sure it's understood that accessible technology is not optional. Support can't be intermittent. Catching up and repairing is impossible. The cost of not participating in all the technology decisions made between now and next March will far surpass the minimal yearly investment. We need a permanent Accessible Technology Program that sustains support for an informed community, technical knowledge that keeps pace with advances, and an understanding of how the systems we all rely upon can be inclusive, so that vital decisions don't exclude us.

An Expert Prognosis: Patients' Rights & Policy Perspectives



Today, a staggering eight million Canadians live with an eye disease, contributing to a dynamic that is putting patients at risk of preventable vision loss and blindness. As the situation becomes more tenuous, three experts provide their perspectives and prognosis on the future of vision health in Canada.



Dr. Jane Barratt, Secretary General, International Federation on Ageing (IFA): *The current policy environment and where advocacy efforts need to be directed.*

Q. With respect to vision health policy in Canada, what are we seeing provincially and what do patients need to be concerned about?

A. What should be most concerning to all of us is how specific health policies that impact the rights of Canadians are being developed, and how vastly different these can be depending on where you live in the country. Challenges for patients and the vision health community are mounting, and with provinces already enacting biosimilar policies, cost appears to supersede patient and physician choice to determine the most appropriate management and treatment for the condition.

Q. How can collective advocacy from allied patient groups and physicians impact policies in the interest of patients?

A. It is only through our collective actions that we truly drive and impact change. Over the past six years, the Eye See You campaign, advocating for options in vision

health is a perfect example of the Canadian community of experts in vision health, policy, and advocacy coming together to prioritize patient rights. With more than one hundred allied groups, the IFA and partners are directing attention to our most urgent health priorities.



Jim Tokos, President, Canadian Council of the Blind: *Informed consent, patient and physician choice.*

Q. Why is it important to ensure Canadian patients and their physicians have 'choice' when it comes to treatment decisions?

A. When it comes to vision, it is so critical that the physician and patient strike the right balance and select a treatment regimen that leverages the latest in science and innovation, to optimize health outcomes. This important discussion about 'choice' becomes increasingly difficult when provincial and territorial policies limit treatment options based on cost.

Q. What role does communication play in discussions between the patient and their physician and why is informed consent so important?

A. I'm on a couple of task forces to ensure that ophthalmologists understand the perspectives of patients and communication between these two groups is simply paramount – communication can remove so much fear from the patient. It is not just a matter of quickly going through the 'fine print', but a meaningful dialogue driven by facts, and a mutual understanding of goals will ensure that the best prognosis is achieved for patients.



Louise Gillis, Past Canadian Council of the Blind President: Reflection and actions to prioritize vision health.

Q. Louise, as former President at CCB, what concerns you the most about changing health policies and their impacts on patients?

A. I've seen it all during my time as past-CCB President and as I look forward and support the future work of the vision health community in Canada, it is paramount that we press on! Complacency is easy and accepting

the status quo may seem inevitable, but in the case the limiting provincial policies, we must remain committed and protect patient's rights.

Q. What does the vision health community need to do now, to prevent these concerns from materializing?

A. There is no going back for patients who experience eye disease, a loss in vision cannot be restored and gains from treatment can be impacted, if for example, a patient is forced to switch to a different mandated therapy, with economics as an underlying driver. We live in Canada and it is our right to have access to the most efficacious treatment, choice should never be restricted and our collective voice will defend these rights.

The IFA and allied partners, including the Canadian Council of the Blind encourage all Canadians to visit the Eye See You website for more information on how regional policies are impacting Canadians vision health. While biosimilars may be an emerging treatment option in ophthalmology, there remain concerns on the limited guidelines and patient education. Should biosimilars be an alternative in the future in the treatment of retinal diseases, patients and health care providers must be equipped with the latest current evidence-based information. There are currently no guidelines and limited clinical data available on the appropriate use when it comes to vision loss treatment. Please visit www.eyeseeyou.care to learn more and how to become an advocate in your region.



Eye See You

Advocating for Options in Vision Health.



Looking for Leadership from the Federal Government for Eye Health, Vision Care, and the Prevention of Blindness: The Benefits of a Vision Desk at the Public Health Agency of Canada

Maintaining good vision is a vital part of overall health and quality of life. The impact of vision loss on an individual is enormous from both physical and mental health perspectives. In fact, 80 percent of Canadians report that losing their vision is their most feared disability. In a 2019 assessment of vision loss in Canada, Deloitte Access Economics found that vision loss and blindness affect 1.2 million Canadians, or 3.2 percent of the Canadian population, at a cost of \$32.9 billion. It's a critical public health issue that has a significant impact on a person's quality of life. It's for this reason that we are advocating for the establishment of an Office for Vision Health or a Vision Desk at the Public Health Agency of Canada (PHAC).

For many years, optometrists, ophthalmologists, researchers, and patient advocates have been engaged in raising awareness about eye health, vision care, and the prevention of blindness among Canadians. The good news is that vision loss can be prevented or treated in 75 percent of cases. Along with other vision partners, the Canadian Association of Optometrists, the Canadian Ophthalmological Society, the Opticians Association of Canada, CNIB, Diabetes Canada, the Canadian Council of the Blind, and Fighting Blindness Canada have worked collaboratively to advocate for those who need eye health and vision care the most: seniors, children, those with low vision and disabilities, Indigenous people, and

low-income families. Access to the full range of vision health services for all Canadians should be provided to ensure their quality of life. We're committed to ongoing collaboration and we recognize that our success is limited without the collaboration and leadership of the federal government.

Led by a Chief Eye Health Officer, the Vision Desk would work with the provinces and territories on strategies for eye health and vision care, along with the full integration of post-vision loss rehabilitation therapy into the health care continuum. Similar to the existing Dental Desk, the Vision Desk would run public education campaigns about eye health issues, serve as a hub for eye health research, and encourage collaboration across all activities with provincial and territorial governments, non-governmental organizations, health professionals, industry, and interested individuals. The Vision Desk could also set priorities or coordinate vision research and translate science into health services, similar to the National Eye Institute in the United States. The Vision Desk would provide a unifying vision for eye health in Canada through the development of a National Strategy for Action on Eye Health and Vision Care.

To make this a reality for all Canadians requires leadership, and a Vision Desk at PHAC represents a positive first step in that direction.

Vision Health Month 2022

PREVENTABLE BLINDNESS



NATIONAL VISION HEALTH STRATEGY

The prevention, research, treatment, and rehabilitation of vision loss requires a national vision health strategy and a coordinated effort on the part of federal, provincial, and territorial governments.



VISION HEALTH DESK

It's essential that Health Canada establish a vision desk within the Public Health Agency to clearly focus government efforts on the prevention, research, treatment, and rehabilitation of vision loss.



INCREASE VISION HEALTH RESEARCH FUNDING

Funding of vision health research in Canada is woefully inadequate. We must invest to find treatments for blinding eye diseases and life-changing technologies for people currently living with vision loss.

Vision Partners Unite to Stop Preventable Blindness

It's time to stop the crisis of preventable blindness. Currently, 1.2 million Canadians are blind, deaf-blind, or partially-sighted, and the number of Canadians living with vision loss is growing every day. Over eight million (that's one in five) Canadians are living with an eye disease that puts them at significant risk of blindness. However, 75 percent of vision loss cases are preventable with early diagnosis and access to treatment. That's why more education about eye health is required for Canadians. It's in our power to end this crisis of preventable vision loss, and we must act now.

The Canadian government's lack of attention on eye health and vision care is having profound implications for individuals, communities, the economy, and our health care system. Prevention of vision loss requires a coordinated effort on the part of governments, individuals, and the health care system. An initiative



Prevention of vision loss requires a coordinated effort on the part of governments, individuals, and the health care system.


of this sort should be based on a national vision health plan, one that incorporates a vision desk dedicated to vision health at the Public Health Agency of Canada. It should also be supported with a substan-

tial increase in funding for vision health research.

The Government of Canada has stood four times before World Health Assemblies — in 2003, 2013, and twice in 2020 — voting to deliver a national vision health plan. More recently, for a fifth time on July 23, 2021, at the UN General Assembly, the Trudeau government, along with 193 countries, unanimously supported a motion calling for “Vision Care for Everyone by 2030.”

We urge the government to keep its long-overdue promise and to develop a comprehensive national plan for vision health in Canada.

The time to act is now. Sign the petition today at STOPVisionLoss.ca. Let's stop the crisis of preventable vision loss and blindness.

The vision loss community and its stakeholders stand ready to assist in developing this national vision health plan. 

Harry Bohnsack

Dr. Harry Bohnsack, President



Jim Tokos

Jim Tokos, National President



Doug Earle

Doug Earle, President & CEO



Colin G. Mann

Colin G. Mann, MD, FRCSC, President



John M. Rafferty

John M. Rafferty, President & CEO



Laura Syron

Laura Syron, President & CEO



Dr. Jane Barratt

Dr. Jane Barratt, Secretary General



Jennifer Urosevic

Jennifer Urosevic, President & CEO



Deborah Gold

Deborah Gold, Executive Director



Robert Dalton

Robert Dalton, Executive Director





SIGN THE PETITION NOW

Go to STOPVisionLoss.ca

STOP THE CRISIS OF
PREVENTABLE BLINDNESS





Vision Rehabilitation Services Are Critical to Canada's Aging Population

Vision Loss Rehabilitation Canada provides a range of programs and services to support Canadians living with vision loss.

Anne Pappmehl

As Canada's baby boomers advance toward their 80s, increasing numbers are facing challenges with their sight.

The Cost of Vision Loss and Blindness in Canada, a 2021 report by Deloitte, estimates that the number of Canadians diagnosed with an eye condition that could lead to vision loss or blindness will increase to 13.8 million by 2050.

The same report notes that the total cost of vision loss in Canada in 2019 was \$32.9 billion and that over half (\$17.4 billion) of that cost was attributed to a reduced quality of life and loss of well-being.

"One of the things people fear most with losing their sight is losing their independence," says Jennifer Urosevic, President and CEO of Vision Loss Rehabilitation Canada (VLRC), a non-profit health care organization that provides rehabilitation

services for individuals living with blindness and vision loss.

Loss of vision doesn't have to mean loss of independence

Aba, 94, was diagnosed with macular degeneration two decades ago, and his vision gradually deteriorated to the point where he could no longer read without a magnifier.

"As a retired academic, my dad always loved to read and learn new things, so when my sister and I noticed he was avoiding it, we raised the issue with his eye specialist at the next visit," says Irit, Aba's daughter.

With the help of the specialist, Aba found his way to VLRC. The family had a three-hour assessment with a VLRC specialist, who introduced Aba to visual aids to make the most of his remaining sight.

"That meeting was a game-changer,"

says Irit. Now, using a closed-circuit TV (CCTV) video magnifier, among other technical aids, Aba is able to enjoy reading his books and emails again. "It's really helped him regain his quality of life and independence," says Irit.

VLRC services help people lead full, independent lives after vision loss

VLRC supports people like Irit's dad who are dealing with acquired vision loss from aging, as well as those who were born blind or with low vision.

"Our main mission is to ensure that we're there every step of the way to help someone experiencing vision loss navigate not only the services they require from us but also other health care services they may need," says Urosevic.

VLRC offers an array of client-centred programs and services, based on the



Our main mission is to ensure that we're there every step of the way to help someone experiencing vision loss navigate not only the services they require from us but also other health care services they may need.

individual's short- and long-term goals. These range from teaching daily living skills and selecting appropriate vision aids or magnifiers to learning how to navigate indoor and outdoor environments safely. The organization also offers concentrated programs designed to fill gaps in community health care programs, such as its Aging in Place Program and its Falls Prevention Program.

A big concern among aging Canadians experiencing vision loss is being a burden to others.

"One of the things we aim to do is wrap our services around giving people choices to live the way they want to, so if that choice is to remain independent at home, we help them with that," says Urosevic.

Thanks to VLRC's services, Aba has been able to continue living on his own.

"It was very much a pleasant surprise to learn about VLRC. Not only has it benefitted our dad, it has benefitted our whole family because my sister and I can take comfort in knowing that our dad is happy, independent, and not feeling like he's a burden to anyone," says Irit.


Support and funding needed on a continuous basis

To meet the demands of our aging population without straining the health

care system, ongoing funding for vision rehabilitation specialized home and community services will be needed.

"This is not a nice-to-have but an essential service, and there's a critical need for people to have timely access to it," says Urosevic. "If you need a hip or knee replacement, for example, there's a prescribed rehab post-surgery plan. Similarly, if you lose your sight, there needs to be support available so people can learn the skills they need to continue living the life that they wish to live."

Looking to the future, Urosevic believes that VLRC can play a significant role in ensuring that other professionals in the health care system also have skills to integrate vision loss into their care plan.

"Through our concentrated programs and by capacity-building with other professionals, we can ensure all the health care needs of our clients with vision loss are being met," says Urosevic. "We have a lot of resources and tools that can benefit the home and community care sector, and we're supportive of integrating our knowledge and expertise with that of other health partners. We want to ensure that when they're providing care to somebody with sight loss, they're taking into consideration the needs of the person." 



Jennifer Urosevic
President and CEO,
Vision Loss
Rehabilitation
Canada



Irit
Daughter of Aba —
Client,
Vision Loss
Rehabilitation
Canada



If you or someone you know has been affected by vision loss, visit visionlossrehab.ca to learn more about vision rehabilitation services.

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REHABILITATION**
CANADA

Healthy Vision Is Everything and Canadians Deserve Full Access to Quality Care

The eyes are the windows to our physical well-being — and vision experts report seeing some troubling developments, especially among older Canadians.

D.F. McCourt

According to a recent research study conducted by Deloitte on behalf of the Canadian Council of the Blind, missed and postponed vision health appointments over the course of the pandemic have led to a rise of retinal diseases like age-related macular degeneration and diabetic retinopathy, threatening the vision of older Canadians. Data shows a 47 percent decrease in all surgeries across Canada, including surgeries for cataracts, glaucoma, retinal diseases, and other diseases with the potential to lead to vision loss.¹

“There’s this myth that, with increasing age, your vision inevitably gets worse and worse until you can’t see at all,” says Dr. Jane Barratt, Secretary General of the International Federation on Ageing (IFA). “The truth is, many of these conditions are preventable. But, because we’ve been in lockdown and facing such severe restrictions, we hear ophthalmologists saying that they’re now seeing advanced stages of disease that could have been avoided with timely checkups and treatments.”

And behind every story or statistic of vision loss, there’s a life made more precarious. In the aging population especially, vision and independence are inextricably intertwined. “When vision changes or vision fails for someone who has had

normal vision, the impact is tremendous and life-altering,” says Dr. Alan Low, Executive Director of Medicines Access Coalition. “People with declining vision describe significant impacts to their life and for some, there’s a complete loss of independence as they’re unable to cope with daily routines and activities.”

A choice of innovative treatments is available — if we have the freedom to choose

Among the most powerful tools available to slow, halt, or even reverse the progress of these diseases are a class of innovative, and frequently costly, biologic therapies known as anti-VEGF treatments. As the patents expire on the original cohort of these ophthalmological biologics, a new class of drugs known as biosimilars is being engineered to provide a more cost-effective option. Fundamentally similar, but not molecularly identical, biosimilars provide exciting new options for treatment, but there’s a lack of information on the risks and contraindications of switching for existing patients.

In some fields outside of ophthalmology, mandatory switching to biosimilars is already policy in some parts of Canada. In British Columbia, for instance, thousands of people living with rheumatic conditions



are waiting to find out if they’ll be able to get an exemption to stay on the medication that’s been successfully managing their condition.

“Coverage across Canada is not consistent and while some provincial plans cover the treatments, others do not,” says Dr. Low. “It’s important to ensure that biosimilar policies that limit which drugs are accessible through a public plan aren’t restrictive, preventing patients and their prescribers from choosing the best therapy for the individual.”

Switching medications is a big decision with a lot of potential consequences. And it’s critical to remember that the switch from a biologic to a biosimilar is, in fact, a change in treatment, even if the desired outcomes are identical. When a person’s vision is on the line, it’s hard to think of




these decisions as being anything other than personal.

“If we want to put quality of life first, decisions around treatment must be based on the tailored assessment and critical examination of a physician talking to the patient about the treatments available,” says Dr. Barratt. “That may lead to using a biosimilar, or it may lead to a biologic.”

Eye See You

The IFA’s Eye See You campaign is a collaborative partnership aiming to clear a path to sensible biosimilar policies across Canada. “The goal of the Eye See You campaign is to improve the vision health of older Canadians,” says Dr. Barratt. “We do that by helping to influence and shape policy across sectors and across disciplines. That includes working with

patient organizations, working with government to understand their policy, and working with leading ophthalmologists across Canada.”

The world looks very different than it did two years ago. But if we still want to like what we see, we need to implement policies that protect the freedom of Canadians and our vision health providers to make the choices that will safeguard our vision. 

REFERENCES


¹ Canadian Council of the Blind. “Addendum to the Summary Report on the Cost of Vision Loss and Blindness in Canada.” August 2021. Available at: <https://ccbnational.net/shaggy/2021/10/12/the-impact-of-covid-19-an-addendum-to-the-cost-of-vision-loss-in-canada-study>. Accessed April 20, 2022.



Dr. Jane Barratt
Secretary General,
International
Federation on
Ageing



Dr. Alan Low
Executive Director,
Medicines
Access
Coalition

 Visit eyeseeyou.care to see how our collective advocacy can shape policies for retinal disease in Canada.



By Hook or By Cook's
Bruce Cook (L) and Christian



Tripping On Air's Ardra Shephard

PHOTOS COURTESY OF AMI

AMI Shines a Spotlight on the Disability Community with *By Hook or By Cook* and *Tripping On Air*

AMI's summer is heating up with a pair of projects that further the company's vision of establishing and supporting a voice for Canadians with disabilities by representing their interests, concerns and values through accessible media, reflection, and portrayal.

Freestyle motocross rider Bruce Cook is on a mission to help others realize their dreams the same way he did: with innovation, modifications, and a lot of determination. In the second season of *By Hook or By Cook*, Bruce is depressed that the COVID-19 pandemic has shut down the activities he loves. After a call from some friends, Bruce and his friend Christian jump at the chance to make a remote lake lodge more accessible.

Season 2 of *By Hook or By Cook* returns June 16, at 10 p.m. Eastern on AMI-tv. Stream *By Hook or By Cook* on AMI.ca and the AMI-tv App.


Fashion Dis host Ardra Shephard brings her confessional and informational blog, *Tripping On Air*, to the podcast space, where she spills the tea on what it's really like to live with multiple sclerosis (MS). Joining Ardra is co-host Alex Hajjar, an MS expert by marriage. Tune in monthly



AMI's summer is heating up with a pair of projects that further the company's vision of establishing and supporting a voice for Canadians with disabilities by representing their interests, concerns and values **through accessible media, reflection, and portrayal.**

as Ardra and Alex explore the dynamic between patients and partners, share chronic illness life hacks, and dish about everything from symptoms to stigma.

Download the *Tripping On Air* podcast from your favourite podcast platform later this summer.

By Hook or By Cook and *Tripping On Air* are the latest original content from AMI, a not-for-profit media company that entertains, informs, and empowers Canadians who are blind or partially-sighted. 



Learn more about AMI, its programming, and where it can be found at AMI.ca, on Facebook ([@AccessibleMediaInc](https://www.facebook.com/AccessibleMediaInc)), on Twitter ([@AccessibleMedia](https://twitter.com/AccessibleMedia)), and on Instagram ([@accessiblemediainc](https://www.instagram.com/accessiblemediainc)).

This article was sponsored by **Accessible Media Inc.**



Sight Loss Prevention Policy Hopes to Support Eye Health of Those with Diabetes

For people living with diabetes, understanding the corresponding risks to their eye health is vitally important.

While insulin has saved and improved millions of lives around the world, it's not a cure. Those living with diabetes continue to face challenging complications, including blindness. Diabetes is the leading cause of preventable blindness in those 20 to 64 years of age. Diabetic retinopathy (DR) is a diabetes complication that affects the eyes and can lead to vision changes or sight loss. Diabetes Canada hopes that just knowing about diabetic retinopathy will help people living with diabetes avoid the risk of sight loss or delay the onset of DR.

May is Vision Health Month and an important time to raise awareness about the sight loss complications of diabetes. During last year's Vision Health Month, Diabetes Canada published a Sight Loss Prevention and Diabetes Policy Statement. As the country's leading diabetes charity and publisher of diabetes clinical practice guidelines, Diabetes Canada developed recommendations for federal, provincial, territorial, and municipal governments, health care providers, and people living with diabetes about DR screening, prevention, and treatment. The goal of the policy is to improve health outcomes for Canadians with diabetes.


Calgary, Alberta's Franca Cupello was diagnosed with type 2 diabetes before age 40 and a decade later was diagnosed with DR. She shared her lived experience with Diabetes Canada to help inform the sight loss prevention and diabetes policy. "Early access to eye health monitoring, together with a solid understanding of the risks related to blindness, are imperative and should be considered part of the early treatment plan for people with diabetes," says Franca. "The Diabetes Canada sight loss prevention policy will help change personal experiences and potentially save the vision for many people with diabetes.

This policy may also serve as a guide for stakeholders — from family physicians to eye care specialists, vision loss agencies, and governments."

"For some people with diabetes, monitoring and maintaining their eye health and having enhanced screening and access to treatment with the support of all levels of government could reduce the onset of DR," says Laura Syron, President and CEO of Diabetes Canada. "But, as the number of Canadians with diabetes increases, the negative impact of DR will become an even bigger burden on those with diabetes and our economy."


For those with DR, further health complications can arise. Sight loss caused by DR is linked to increased falls and hip fractures, for example. Additionally, some populations are at greater risk of sight loss caused by DR. Compared to other Canadians, people living in northern, remote, and rural communities, Indigenous Canadians, and visible minorities experience far more sight loss caused by DR.

There are several other factors that increase the risk of DR. These include how long someone has had diabetes, whether their A1C is above their target range, high blood pressure, unhealthy levels of one or more kinds of fat (lipid) in the blood, low blood count (or anemia), being pregnant with type 1 diabetes, and high levels of protein in the urine. Effective management and treatment of these factors can slow the damage from DR.

A national framework to address diabetes — committed to by the federal government and supported by all provinces and territories — could help to improve access to eye health care, prevention strategies, screening, and treatment for people with diabetes. 



Franca Cupello

 For more information about eye care for people with diabetes and the sight loss prevention policy, visit diabetes.ca.

This article was sponsored by **Diabetes Canada.**

**DIABETES
CANADA**



Are You Living with Diabetes? Take an Active Role in Protecting Your Vision Health

For people living with uncontrolled type 1 and type 2 diabetes, an excess of blood sugar can damage or block the tiny blood vessels in their retina, resulting in a condition called diabetic retinopathy. The most common form of vision loss associated with diabetes, diabetic retinopathy affects approximately one million Canadians, making it the leading cause of blindness among working-age adults.

Diabetic retinopathy can develop into diabetic macular edema (or DME), a complication that occurs when blood vessels in the retina leak fluid, causing the macula, which is the central part of the retina, to swell. This extra fluid can cause vision to become blurry and can even lead to blindness.



Symptoms of DME include blurry or distorted vision, seeing **more floaters and colours appearing washed out.**

Symptoms of DME include blurry or distorted vision, seeing more floaters and colours appearing washed out. However, as DME is typically asymptomatic in the early stages, those affected could unknowingly live with this condition while their vision deteriorates over time.




The longer somebody is diabetic, and the less well-controlled it is, the more likely they are to run into vision problems from their diabetes.

“DME is insidious because it happens over time,” explains Dr. Peter Kertes, MD, ophthalmologist and retinal specialist at Sunnybrook Health Sciences Centre in

Toronto. “The longer somebody is diabetic, and the less well-controlled it is, the more likely they are to run into vision problems from their diabetes.”

People living with diabetes must play an active role in helping manage not only their diabetes but their vision health as well. “It’s important that people with diabetes get screened regularly for diabetic retinopathy and DME — not just at the time of diagnosis, but at regular intervals thereafter,” stresses Dr. Kertes.

While DME is a manageable condition, sight cannot be restored once lost. “If they start out with bad vision, it’s unlikely that their vision will be normalized,” explains Dr. Kertes.

Beyond its physical impact, vision loss can also have wide-ranging effects on a person’s quality of life, including mental health, loss of independence, and social isolation. This added psychosocial burden makes it even more imperative for vision health to be a priority for people living with diabetes. 



If you or your loved one are living with diabetes, it’s important to prioritize your vision health and monitor any changes as part of diabetes management.

Taking Care of Your Personal Eye Care Backlog

Many Canadians missed essential eye exams and treatments during the pandemic, and now it's time to get back on track.

Keith D. Gordon, Ph.D.

If you're like most people, you and your family haven't managed to keep your regular appointments with your ophthalmologist or optometrist during the pandemic. You're not alone. A study conducted in 2021 estimated that nearly three million fewer visits to optometrists were made across Canada in 2020 compared with the previous year. In addition, almost 70,000 fewer injections of the treatment for age-related macular degeneration or diabetic retinopathy were administered and 143,000 fewer eye surgeries were conducted in 2020.


Now is the time to take care of your personal backlog. Eye doctors across the country are working extra hard to overcome the backlog that the pandemic has created, so it's possible to get an appointment for that essential treatment or eye examination.

A regular, complete eye examination is essential for your eye health. Many eye diseases can only be detected through a complete eye examination, and it's esti-

imated that 75 percent of vision loss can be prevented or treated if diagnosed early enough.

Very few children have had an eye test of any sort during the pandemic and many have also spent an inordinate amount of time in front of screens. As our children return to school, it's important to make sure that their vision is the best it can be and that there's no underlying condition that may lead to vision loss.

If, for some reason, you've had a break in taking regular eye drops for an ocular condition such as glaucoma, it's essential that you recommence taking your medication and, if you've missed getting your regular eye injections or have postponed your cataract surgery, make an appointment with your ophthalmologist right away to make sure you haven't lost any vision and to ensure you get the treatment you need.

As we arise from the slumber of the past couple of years, taking care of our eye health needs to be a priority for us all. 



Keith D. Gordon
Ph.D.,
Senior Research
Officer,
Canadian Council
of the Blind



Thank You - We Couldn't Do It Without You

The Canadian Council of the Blind wishes to express its most sincere appreciation and gratitude to our sponsors for their important contributions and ongoing support. We couldn't do it without you.

Together we are working to "change what it means to be blind" and that's important. Again, thank you!

Vision Health Month Sponsors:



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

By: Catherine Langlois
Senior Advisor of Universal Accessibility, VIA Rail

VIA Rail representatives welcomed accessibility advocates on board a mock-up of the interior of their new fleet of trains in 2019.

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

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

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

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

Highlights of the 2022-2025 accessibility plan include:

- The creation of American Sign Language (ASL) and Langue des Signes Québécoise (LSQ) videos on VIA Rail's website
- Ongoing accessibility awareness training for all our employees, from on-train service, to customer care, to office employees and executives
- Improved equity in recruitment by removing bias in the hiring process and making our accessible hiring policy more visible to job seekers
- An accessible procurement process to incorporate accessibility early on in decision-making before projects are launched

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

In addition to seeking input on this plan, VIA Rail has also established an advisory committee on universal accessibility. This committee is made up of various disability groups and will play a key role in the planning of future VIA Rail projects.

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

CANADIAN COUNCIL OF THE BLIND

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Achieving a Barrier-Free Canada by 2040

By Michael Baillargeon

Through the implementation of the Accessible Canada Act on July 11, 2019, the Government of Canada continues to make important progress toward creating a barrier-free Canada where everyone has an equal opportunity to thrive and participate.

On April 4, 2022, Karina Gould, the Minister of Families, Children and Social Development, announced the appointment of Stephanie Cadieux as the first Chief Accessibility Officer (CAO) for a term of four years. Cadieux is a change leader, an advocate for diversity, accessibility, and disability inclusion, and an entrepreneur with more than 15 years of experience in planning and leadership roles. In making the announcement, Minister Gould remarked:

“Stephanie Cadieux’s wealth of experience will be a tremendous asset to the Minister of Employment, Workforce Development and Disability Inclusion. With her support, the Government of Canada will continue to build an inclusive and barrier-free Canada where persons with disabilities have the right to greater equity in society and to play a greater role in the economy.”

Cadieux served as a member of the Legislative Assembly of British Columbia from 2009 until 2022. She was the Minister of Children and Family Development from 2012 to 2017, and between 2010 and 2012, she held various positions, including Minister of Social Development; Minister of Labour, Citizens’ Services and Open Government; and Minister of Community, Sport and Cultural Development.

Prior to her engagement in provincial politics, Cadieux was the director of marketing and public relations for the BC Paraplegic Association from 2004 until 2009. She was also the provincial peer coordinator for this organization from 2001 until 2004. Cadieux is a member of the disability community, having used a wheelchair since the age of 18. Her lived experience allows her to have a deep understanding of accessibility issues faced by people with disabilities.

According to the 2017 Canadian Survey on Disability, there are 6.2 million Canadians aged 15 and older who have a disability. More than 1 in 10 youth in Canada have one or more disabilities.

This appointment will support the government’s efforts to prevent and remove barriers to accessibility and to increase opportunities for persons with disabilities to contribute to their communities and workplaces. The Accessible Canada Act includes seven priority areas: employment; the built environment; communication; information and communication technologies; the procurement of goods, services, and facilities; the design and delivery of programs and services; and transportation.

To help meet the Act’s objective of realizing a barrier-free Canada by 2040, the government is developing a Disability Inclusion Action Plan. It will also focus on reducing poverty among Canadians with disabilities, getting more persons with disabilities into good-quality jobs, making it easier for persons with disabilities to access federal programs and services, and fostering a culture of inclusion.

Serving as a special advisor to the Minister of Employment, Workforce Development and Disability Inclusion, the CAO will provide advice on wide-ranging accessibility issues and will monitor and report on progress made under the Accessible Canada Act. The CAO will provide an annual report to the Minister detailing outcomes achieved under the Act, as well as systemic and emerging accessibility issues. The Office of the CAO will be established as a trusted source of information on accessibility, with the CAO being responsible for promoting a positive and productive dialogue between the federal government, disability stakeholders, and national and international organizations.

The Toronto Visionaries' Experience Expo Is Back!



Photo by Marian Green

On Saturday, May 28, 2022, the Canadian Council of the Blind (CCB)'s Toronto Visionaries Chapter will host the 2022 Experience Expo, the only major exposition and consumer show for people with vision loss in Canada. The Experience Expo is an interactive, hands-on exhibition featuring dozens of exhibitors, products, and services covering every aspect of the experience of living with vision loss, and is open to those with seeing disabilities along with their friends and families.

"It feels great to be planning a major public event after being locked down for the past two years," says Ian White, CCB Toronto Visionaries Chapter President. "The pandemic has hit those with disabilities really hard. Especially for people with vision loss, it's meant greater isolation and restricted access to everything from health care to supports and services."

As an organization dedicated to breaking the isolation that so often accompanies vision loss and that promotes peer-to-peer mentoring and the building of social networks

for those with visual impairment, the CCB Toronto Visionaries has seen how COVID restrictions have disproportionately impacted the blind community.

"It feels fantastic to finally be able to come together face-to-face as a community again, to share information, to see the range of supports and services available to those with vision loss, to see what's possible, and to celebrate our resilience in the face of adversity," says White. "It's what the Expo is all about!"



Photo by Marian Green

What can you find at the Experience Expo? Coming to the Expo gives you the chance to get connected with information on new

adaptive technologies, recreation and leisure, tactile art and accessible entertainment, sport and fitness, transportation, education, employment, government supports, advocacy issues, and more.

The Experience Expo is an all-day event comprised of the consumer show, followed by the Expo Vision Forum, a panel discussion presented by the CCB. The day closes out with a celebratory community dinner for all guests and exhibitors, with a cash bar, music, and a grand prize draw.

Experience Expo Times:

**EXPERIENCE EXPO
CONSUMER SHOW:**
11:00 a.m. - 3:30 p.m.

EXPO VISION FORUM:
4:00 p.m. - 5:30 p.m.

**VISIONARIES COMMUNITY
SOCIAL DINNER:**
6:00 p.m. - 8:00 p.m.

Registration is not required for the Expo, but is required for the Expo Vision Forum and the Community Social Dinner. See the Visionaries website at www.ccbtorontovisionaries.ca for more information and registration details.

The Experience Expo will be held at the Miles Nadal Jewish Community Centre, 750 Spadina Avenue, Toronto, at the corner of Bloor Street West and Spadina Avenue. Admission is free. All are welcome!

Shayla Brown, a visually impaired actress, makes her Toronto stage debut

By Aisling Murphy, *Toronto Star*

Blind actress Shayla Brown recently co-starred in “Orphans for the Czar” at the Crow’s Theatre

Shayla Brown is a new Toronto resident. She’s a Taylor Swift fan with a particular fondness for the pop star’s 2010 coming-of-age album, “Speak Now.” She’s an 18-year-old actress racking up credits across stage, film, and TV.

Blind since birth, she’s also an advocate for better representation of the visually impaired.

Brown is a week into her Toronto theatre debut, starring as Rayisha alongside stage veteran Eric Peterson in George F. Walker’s comedy “Orphans for the Czar,” inspired by Maxim Gorky’s novel “The Life of a Useless Man” and set in St. Petersburg at the cusp of Bloody Sunday in 1905.

“It’s been exhausting, but such a good experience,” Brown says.

The play finished a successful run this last April 17 at the Crow’s Theatre in the Streetcar Crowsnest, one of Toronto’s more gorgeous theatre facilities, was a far cry from Brown’s first foray into the performing arts: “The Boy Who Cried Wolf,” at the Midland Cultural Centre, in which she played a sheep. She was seven.

Since then, she’s maintained a busy schedule, recently appearing in an episode of Apple TV+’s “See” with Jason Momoa. She’s also featured in

the upcoming Sarah Polley-directed drama, “Women Talking.”

For Brown, working at Crow’s has been instantly formative. “My favourite moment was getting to use the set for the first time,” she says. “The rehearsal space was very different from the set, which has a lot of wood. I couldn’t really imagine how that would feel until I was there.”

Brown didn’t have to navigate the move to the new set alone: she’s been accompanied by her service dog, Libby. “She’s not onstage with me,” Brown says, “but she helps me get from one place to another. When I’m rehearsing, she’s lying in the corner. It’s surprised me how chill she’s been. It’s a lot, and it’s loud, and we’re all constantly bringing up these big emotions. I was so worried how she’d react to that, but she just doesn’t care.”

Her family has been supportive – if a little nervous – of the Midland-born actress’s move to the city. It’s a new level of self-sufficiency for which Brown has fiercely advocated, but she’s also grateful for her support system: in the first week of rehearsals, her grandfather drove her to the theatre from her aunt’s home in Mississauga every day.

“That was a big help since I was still getting acquainted with the Crow’s space,” Brown says. “Now I’m living in Toronto proper with other people, but as a guest. I’m on my own. I finally get to exercise my independence. I’m an adult, and I want to be able to do this.”

Brown says her visual impairment has prompted conversations among her and her collaborators on how best to address her needs. “I think that the most important thing is to





Shayla Brown and Eric Peterson in a scene from "Orphans of the Czar," directed by Tanja Jacobs. DAHLIA KATZ PHOTOS

not be afraid of it," she says. "Don't be nervous to ask the big questions, the hard ones. As long as you ask in a way that's polite and sensitive – it's only going to make the story better."

According to Brown, "See," about a futuristic society in which everyone has lost their sense of sight, is a show that handles disability, particularly blindness, right.

"I loved my experience on that show," she says. "They have a visually impaired consultant and producer on the show all the time." The production also has choreographers to make sure seeing actors are portraying sightlessness respectfully.

Apple TV+ has received much praise for its handling of disability on-screen. Its Academy Award-winning best picture, "CODA," has catapulted the streaming service to the forefront of conversations about representation in film.

"Troy Kotsur's win at the Oscars (for best supporting actor) was so important for the deaf and hard-of-hearing children who will see themselves represented on that stage," Brown says. "I wish I'd had that as a kid, seeing a blind person win something big like that."

Brown's Crow's debut is but one in a series of projects that gestures toward a long and vibrant career. Whatever's next for Brown, she'll likely approach it with an inspiring amount of clarity and grace. As for her disability, it's perhaps the thing she's least worried about.

"So many people's reaction to me wanting to stay in this industry is, 'Oh, that's going to be really hard for you.' I've been told it's going to be harder for me more times than I can count. Whatever. Everything's hard," Brown says with a smile.

"I can do this."

Blind Tech and the Outdoors

By Lawrence Gunther Euteneier



As someone who has spanned the visual frontier from vision-impaired to functionally blind to living without sight, I've had plenty of opportunities to try different adaptive technologies. Sadly, most accessibility tech is meant for use indoors or at most in urban or built communities. Few have what it takes to be used off-grid, and by that, I mean everything from hiking trails to water adventures to traversing frozen lakes. I'm not sure why, but tech developers seem to be under the impression that those of us with vision loss seldom leave city sidewalks or venture beyond a street map. You're probably thinking that surely there must be something out there that would make outdoor adventures that much more accessible, doable, and safe.

First off, I'm an admitted guide dog lover and have been since 1986 when I got my first Lab. No offence to white cane users, but sometimes dogs just rule. I'm not the only one who thinks this.

A few years back I was disembarking from a flight into Canada's Arctic. As I was saying thanks to the flight attendants prior to exiting, one handed me a white cane equipped with a tiny sonar dish positioned just below the handle. I explained that the cane was not mine. Her reply surprised me when she said, "Just take it, it's been in our coat closet for weeks now and we have no idea who it belongs to." No doubt, some blind Inuit or First Nations traveller abandoned the tech on their return home. The experience spoke volumes to me about just how useful something like this would be in a community with no sidewalks or roads. I discovered that for many, their preferred orientation aid was the shaft of a hockey stick with the blade removed – the only white cane that wouldn't snap in half if the tip got lodged in a snow drift. It also serves as a walking staff.

It turns out guide dogs that far north also weren't common for two reasons. First of all, they can easily be injured

in fights with sled dogs running loose. Labs also have insufficient belly fur to protect their more sensitive parts from extreme low temperatures. Venturing blind off-grid also has its pitfalls, as I was to learn later.

My non-sighted Inuit host and I were attempting to traverse from his home to the local Hudson Bay Store in Tuktoyaktuk, Nunavut. Somehow, we got turned around only to be discovered later by an observant Inuit man in his truck who spotted the two of us heading away from the community.

In reality, I spend way more time south of the Arctic Circle aboard boats and other watercraft of all shapes and sizes. Many of my boats are equipped with electronics featuring GPS, bathometric maps, and sonar to show depth. This is basic equipment found on most sailboats and fishing boats. Radar too is now becoming more commonplace. Electric trolling motors are also standard equipment on most fishing boats, and these too now include GPS, access to digital maps, and transducers for indicating depth below motor, and can now be operated remotely. All of these technologies are perfectly suited for use in wet weather, bumpy conditions, and extreme sun. I wish I could say the same for the accessible electronic aids that I've experimented with over the past 15 years.

With few exceptions, very little tech designed for the blind has been "ruggedized." One exception is the various

iterations of the GPS tracker systems developed by HumanWare. Not so with the different talking and audio compasses I've tried, most of which fail when exposed to water. Thankfully, advances in smartphone designs now mean these devices can withstand the occasional underwater dosing because, let's face it, falling off docks or out of canoes and kayaks does happen.

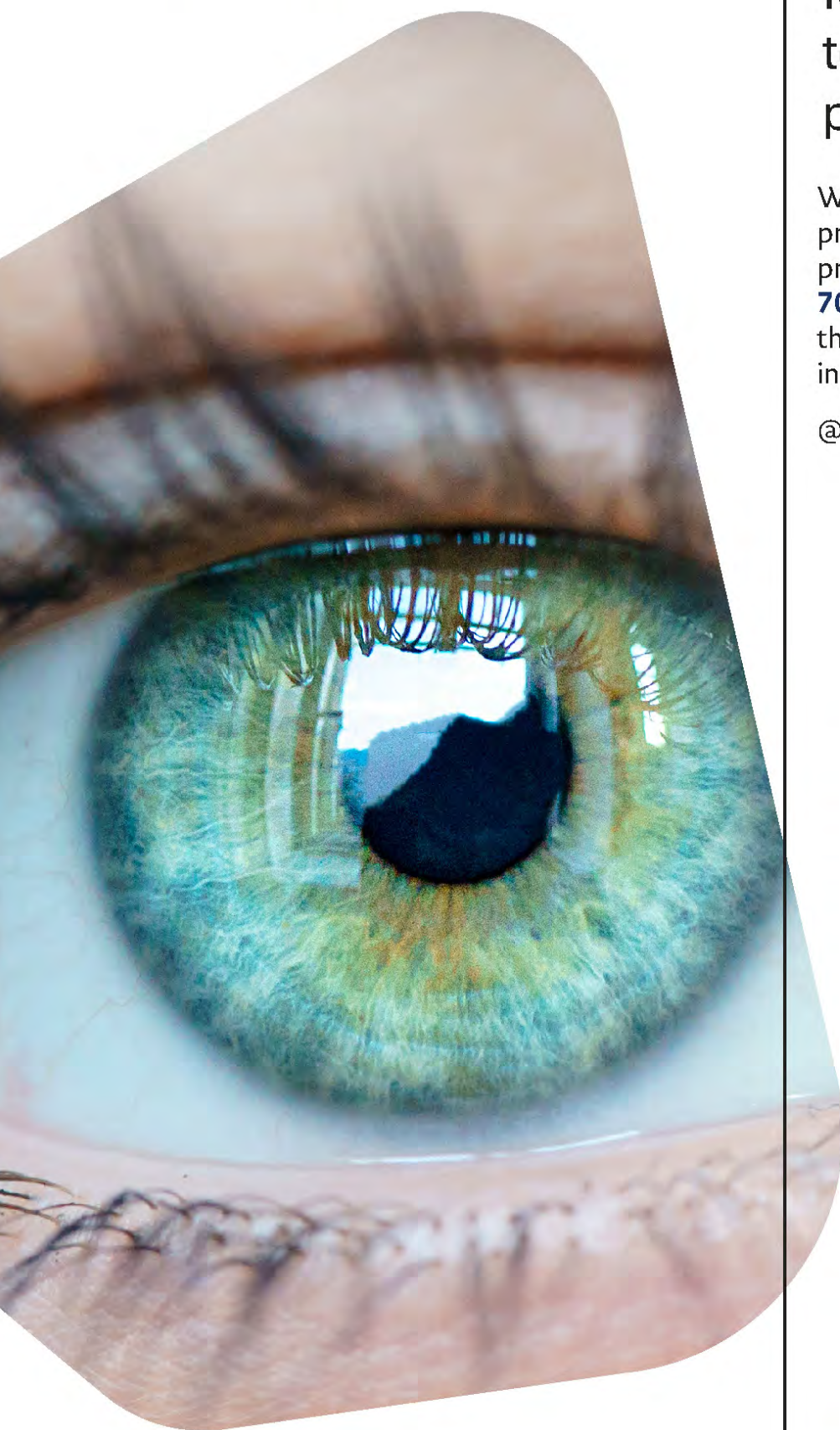
On the topic of compasses, if you're going to depend on downloadable compass apps, and there are plenty to choose from, be sure you bring lots of backup battery support. I've tried a lot of these apps and my favourite is still the one that comes with the iPhone.

As far as GPS apps go, with the exception of a few, all the rest are limited to turn-by-turn directions based on street maps. Very few, such as the Soundscape app from Microsoft, can navigate over land and water using pre-recorded markers.

If you want to know more about the technologies I've experimented with over the years, visit my website at BlindFishingBoat.com. Read the Blind Boating blogs. There are plenty of real-world field reports. And please, if you have technology that you think I should know about or try, contact me at Info@BlindFishingBoat.com.



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The Canadian Ophthalmological Society (COS) (www.cos-sco.ca) is the national, recognized authority on eye and vision care in Canada and represents over 1000 of Canada's eye physicians and surgeons. We are committed to providing optimal medical and surgical eye care for all Canadians by promoting excellence in ophthalmology. We work collaboratively with government, other national and international specialty societies, universities, and other eye care professionals and patient groups to advocate for health policy in Canada in eye and vision health.

An ophthalmologist is a Doctor of Medicine who specializes in the diagnosis and treatment, both with

recent study, the Conference Board of Canada estimated that in 2020, ophthalmic interventions saved a total of \$6.4 billion: \$1.6 billion in health care costs and \$4.8 billion in indirect costs to society. With Canada's aging population and an increasing demand for eye care, total savings are projected to more than double by 2040.

Canadian ophthalmologists are at the forefront of innovation in eye care. They are leaders in international and national clinical trials for potential treatments, sought-after experts at medical conferences, researchers and scientists involved in cutting-edge investigations, and global medical citizens who participate in providing eye care and medical training in developing countries around the world. Exciting work is happening across Canada in areas such as gene and stem cell therapies for genetic eye conditions, implantable devices and prosthetics, corneal transplants, teleophthalmology consults for patients in remote locations, minimally invasive surgical techniques to reduce healing time, and more.

The future of eye care in Canada is bright and Canadians can have confidence that ophthalmologists will be there, working collaboratively with all members of the eye care team, from coast to coast to coast when their patients need them.

The Conference Board of Canada estimated that in 2020, ophthalmic interventions saved a total of \$6.4 billion

medicines and with surgery, of disorders of the eye. In addition, ophthalmologists can diagnose and manage diseases that may present with signs or symptoms in the eye.

Every year in Canada, ophthalmologists perform over one million procedures to prevent vision loss or restore vision. Preserving sight also prevents injuries or other health care needs associated with vision loss, such as falls, hip fractures, depression, anxiety, admission into long-term care, and use of home care services. These negative outcomes are associated with significant hospital, physician, and drug costs. Therefore, treating vision loss leads to direct cost savings to health care systems. In a



RESOURCES FOR PATIENTS AND THE PUBLIC

See *the Possibilities* (www.seethepossibilities.ca) delivers a wide range of resources and patient stories on a variety of vision health topics including age-related macular degeneration, cataracts, diabetic retinopathy, glaucoma and eye injury.

Eye health in Canada: An invisible crisis

98%

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

1.2
MILLION

Canadians living with vision loss

8+
MILLION

Canadians at risk of eye threatening conditions

\$32.9B

Annual cost of vision loss

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

Making eye health, vision care and rehabilitation services a population health priority requires meaningful federal support.

What leadership looks like:



An evidence-based strategy supported by a vision desk



Increased research funding



A consistent and reliable supply of medication required to treat eye disease and/or conditions



Enhanced access to care for Indigenous peoples and priority populations



Funding to support eye health awareness

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





Funding Research Is Core to Fighting Blindness Canada

By Doug Earle and Larissa Moniz

Fighting Blindness Canada (FBC) is the largest charitable funder of vision research in Canada. Over its 48-year history, FBC has contributed critical funding for the development of sight-saving treatments and cures for blinding eye diseases. By raising and stewarding funds, FBC is driving research forward to understand why vision loss occurs, how it can be slowed, and how sight can be restored.

In 2022, FBC is investing over \$2.6 million in 34 research projects to drive innovation forward across the spectrum of vision research, giving hope to more Canadians.

The team at FBC believes that, while it starts with research, it doesn't end there. The organization is committed to ensuring that once new and innovative treatments are developed, Canadians can benefit from them. FBC is committed to increasing access to early diagnosis to reduce preventable vision loss, and it's committed to ensuring that vision research and vision health are a national priority.

Over 8 million Canadians are currently at risk of blindness, with this number expected to rise to 13.9 million by 2050. This has only been made worse by the pandemic due to cancelled appointments and delayed surgeries. It's estimated that 1,437 Canadians experienced vision loss because of the pandemic. It's clear that Canada is experiencing a crisis of preventable blindness.

It's with the vision loss community in mind that FBC will be back on Parliament Hill during May Vision Health Month. Along with its vision health partners, FBC will be

advocating the federal government to fulfill its promise of creating a National Vision Health Plan. This is crucial to ensure that eye health, vision care, and rehabilitation services are national and federal priorities. Together we can, and must, stop this crisis. Please visit stopvisionloss.ca to sign the petition advocating for a National Vision Health Plan.

FBC is also working to increase investment in vision research in order to address our country's vision health crisis. The Cost of Vision Loss and Blindness in Canada report shows that government spending on vision research is less than \$21 million annually – a paltry amount that doesn't match the \$32.9 billion social and economic impact that blindness has on Canada each year.

FBC represents a diverse and thriving community of individuals, families, volunteers, scientists, and clinicians. Join FBC to raise awareness and funds for vision research. Learn more about eye health at one of its education events or pose your vision questions to FBC's health information line. Together, let's move research forward.

Learn more at fightingblindness.ca



**FIGHTING
BLINDNESS
CANADA** | **VAINCRE
LA CÉCITÉ
CANADA**

AN EYE ON THE FUTURE

TODAY 95% OF AVOIDABLE BLINDNESS CAUSED BY DIABETES IS SOLVED WITH A CLICK¹.



DIAGNOS INC IS REDEFINING DIGITAL HEALTHCARE WITH ARTIFICIAL INTELLIGENCE BY ASSISTING EYE CARE PROFESSIONALS.

By Riadh Kobbi and Guillermo Moreno

High blood sugar, a hallmark of diabetes, is known to lead to progressive damage to the retina. Known as Diabetic Retinopathy (DR), a common cause of blindness in adults, DR affects around 4 patients out of 5 who had the disease for over 20 years. The disease progresses asymptotically until irreversible vision loss occurs and it often goes undetected because of bottlenecks in screening.

Over the past 15 years, multiple national screening programs have been developed using digital fundus photography. Effective screening of diabetes has been proven to reduce the risks of visual impairment and the severity of the complications.

Diagnos Inc. has developed, by using Convolutional Neural Networks (CNN), an Artificial Intelligence (AI) analysis platform that integrates with existing equipment and processes to enable early detection, triage, and monitoring of Diabetic Retinopathy (DR) by automatically grading the severity of indicators found in images of the retina with high accuracy. Diagnos' Computer Assisted Retinal Assessment (CARA) platform is already providing decision support to eye care professionals at IRIS, as well as for triage purposes at the Department of Endocrinology at the University of Montreal Hospital Centre (CHUM).

"The advantage of this technology is that it allows us to screen for Diabetic Retinopathy and only refer patients that truly require specialized care rather than flooding all the Ophthalmology clinics with patients that do not have any pathology", said Dr. Andree Boucher, Chief of Endocrinology Department at CHUM.

"The patient receives a retina picture in the Endocrinology department, images are taken on-site and sent through the CARA platform, which then outputs the report. This is a much more efficient way of operating"², confirmed Dr. Salim Lahoud, Chief of Ophthalmology Department at CHUM.

In June 2021, Mr. Eric Babin, President of IRIS (New Look Vision Group Inc.) among others, commented: "The combination of technological advancement and clinical expertise will help elevate the health care experience and improve patient outcomes."³

Diagnos' CARA platform, installed in the data center in Montreal, examines the retina images of patients. The patient's retina images are transmitted using a secure internet connection. Diagnos then provides the results of the AI-assisted examination back to the eye care professional in the form of a report. The eye care professional may then use the results of the report to assist in managing treatment and potential referral to assist in diagnosis and follow-up of patients with a diabetic condition.

Last December, Diagnos announced the STROKE project, a clinical trial study in collaboration with CommonSpirit Health Research Institute (USA). An early proof-of-concept, the project aims to show potential in the early detection of stroke through the analysis of the retinal microcirculation.

WHAT'S NEXT?

In 2022 Diagnos continues to innovate and improve eye health by focusing on the early detection of Glaucoma, Age-related Macular Degeneration (AMD), and Hypertensive Retinal Changes.

1. International Diabetes Federation (<https://idf.org/>)
2. https://www.youtube.com/watch?v=J8TRX9b_-il
3. <https://www.sedar.com/DisplayCompanyDocuments.do?lang=EN&issuerNo=00003037>

BY HOOK OR BY COOK RETURNS TO AMI!

BRUCE COOK IS BACK FOR SEASON 2!

BY HOOK OR BY COOK

Tune in to find out what adventures Bruce and his friends have been up to.

Season 2 of the award-nominated *By Hook or By Cook* premieres June 16 at 10 p.m. Eastern on AMI-tv.

Visit AMI.ca or the AMI-tv App to watch your favourite AMI programs

Connect with us on social



ENTERTAINS EMPOWERS INFORMS



AMI outlines its plans for a sizzling summer of content

With summer quickly approaching, AMI has lined up a sizzling programming schedule equal to the warmer weather. From returning favourites to debuts that will have you hooked, AMI furthers its vision to establish and support a voice for Canadians with disabilities, representing their interests, concerns and values through accessible media, reflection and portrayal.

JUNE

WE ARE ONE DEBUTS JUNE 2 AT 8:30 P.M. EASTERN ON AMI-TV

Every family is unique. In this AMI-tv series, viewers meet Canadian families that include members of the disability community as they share stories of adapting, growing and supporting each other.

SEVEN FEET OVER DEBUTS JUNE 15 AT 8:30 P.M. EASTERN ON AMI-TV

In the first season of Seven Feet Over on AMI-tv, viewers follow the lives of Vincent, Pascal, Martin and David, four men who stand head and shoulders above the crowd, literally, because of their height.

BY HOOK OR BY COOK RETURNS JUNE 16 AT 10 P.M. EASTERN ON AMI-TV

Bruce Cook, a stunt motocross rider who is disabled, wants to help others with disabilities enjoy life's possibilities with unique innovations that he and his friend, Christian, create. In the second season of By Hook or By Cook on AMI-tv, Bruce is depressed that the COVID-19 pandemic has shut down the activities he loves. After a call from some friends, Bruce and Christian

jump at the chance to make a remote lake lodge more accessible.

Working with Christian, who has been a wheelchair user for 25 years, Bruce learns about perseverance. He also learns valuable lessons from people who are also struggling with the results of a disability which, over the course of the season, will allow Bruce to gain more insight into who he is at his core and what his abilities really are. He learns more about himself, his spirit and his tenacity than he's ever imagined.

POSTCARDS FROM RETURNS JUNE 24 AT 7 P.M. EASTERN ON AMI-TV

Go on exciting adventures from the comfort of your own home on AMI-tv and join AMI's Bureau Reporter Alex Smyth as he travels across Canada, celebrating our country's diverse cultures and experiences. Upcoming destinations this summer include the Rocky Mountains, Winnipeg and Northwest Territories. No passport needed!

SEEING MUSIC DEBUTS JUNE 29 AT 10:30 P.M. EASTERN ON AMI-TV

Go on a musical journey across Canada and around the world on AMI-tv, meeting blind and partially sighted musicians for whom music is not



Postcards From host Alex Smyth

only a passion, but a way of living.

OUR COMMUNITY RETURNS JUNE 30 AT 8 P.M. EASTERN ON AMI-TV

An all-new season of Our Community once again highlights the people, places, organizations or things that have made life more enjoyable for Canadians living with a disability. Upcoming episodes on AMI-tv explore why children with disabilities aren't being properly represented in children's literature in Canada; the W. Ross Macdonald School's renowned music program in Brantford, Ont.; and the cast of characters at Real Wheels Acting Academy, a one-of-a-kind program focusing on professional training and empowerment for local actors in the disability community in Vancouver.



Level Playing Field host Greg Westlake (right)

JULY

MIND YOUR OWN BUSINESS DEBUTS JULY 6 AT 8 P.M. EASTERN ON AMI-TV

Hosted by entrepreneur Kevin Shaw, who is blind, each episode of Mind Your Own Business on AMI-tv takes viewers into the life of a business owner in the disability community as they share their journey of how they came to run their own company. And, with the help of a mentor, they'll aim to take their business take to the next level.

LEVEL PLAYING FIELD RETURNS JULY 11 AT 8 P.M. EASTERN ON AMI-TV

Paralympian Greg Westlake returns as host, introducing AMI-tv viewers to the athletes, community groups, healthcare professionals and grassroots innovators who demonstrate a desire to help drive positive social change through sport. Sports and individuals featured in Season 2 of Level Playing Field include para surfing, pickleball, VOLT Hockey, ParaGolf Canada founder Todd Keirstead and Canadian biathlete and para-Nordic skier Mark Arendz.

DISH WITH MARY RETURNS JULY 12 AT 8:30 P.M. EASTERN ON AMI-TV

Mary Mammoliti—a home cook and food blogger who is partially sighted—knows her way around the kitchen. Can she navigate her way through a cook-along with Canadian chefs? In the second season of Dish with Mary on AMI-tv, Mary connects with chefs from across the country to create mouth-watering recipes, share tips and a laugh or two.

TRIPPING ON AIR PODCAST DEBUTS ON AMI-AUDIO

Fashion Dis host Ardra Shephard brings her confessional/informational blog, Tripping On Air, to the AMI-audio podcast space where she spills the tea on what it's really like to live with Multiple Sclerosis (MS). Joining Ardra is co-host Alex Hajjar (Social Animals podcast), an MS expert by marriage. Tune in monthly as Ardra and Alex explore the dynamics between patients and partners, share chronic-illness life-hacks, and dish about everything from symptoms to stigma. Tripping On Air invites the cool kids of chronic illness to hang out, have a laugh, learn some tips, and above all, feel seen.

AUGUST

EMPLOYABLE ME: WHERE ARE THEY NOW? DEBUTS AUGUST 5 AT 7 P.M. EASTERN ON AMI-TV

In this follow-up to the award-winning AMI-tv series, viewers catch up with job seekers from past seasons for an update on their employment and personal lives.

BEYOND THE FIELD RETURNS AUGUST 8 AT 8 P.M. EASTERN ON AMI-TV

Beyond the Field, hosted by Paralympians Greg Westlake and Travis Murao, examines important issues impacting the world of parasport. Topics covered in the second season of Beyond the Field on AMI-tv include Paralympic funding in Canada versus Olympic funding, training and competing during a global pandemic and myths and misconceptions of making it to the Paralympic Games.



Tripping On Air podcast host Andra Shephard

SEPTEMBER

KELLY AND COMPANY BECOMES KELLY AND RAMYA

It's official! AMI-audio's Kelly and Company is changing its name to Kelly and Ramya. What won't change? Hosts Kelly MacDonald and Ramya Amuthan conducting Interviews and leading discussions about the arts, entertainment and lifestyle issues that matter to you with members of the community. Join the conversation and have your voice heard. And stay tuned for more exciting news about Kelly and Ramya later this year.

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

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

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

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

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

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

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

We're looking forward to meeting audience members, supporters, partner organizations and representatives of the blind and partially sighted community at many virtual events and conferences in the coming months.

Visit AMI.ca, AMItel.ca or email info@ami.ca to learn more about AMI. Follow AMI on Facebook (@AccessibleMediaInc), Twitter (@AccessibleMedia) and Instagram (@accessiblemediainc).

Canada Family Tour World to Store Rich Memories Before Children Go Blind

By Leyland Cecco, *The Guardian*

Last week, as the sun set over the craggy hills of Spitzkoppe, Namibia, Edith Lemay and her husband, Sébastien Pelletier, stared out over the vast landscape. The Canadian couple and their four children had spent the day scaling boulders, then cooled off from the desert heat in a nearby rock pool.

“There was a sweetness hanging in the air and as the sun disappeared, it gave way to more stars than we’ve ever seen in our lives,” said Lemay. “It was just ... magic.”



First stop on the family’s globetrotting tour was Namibia. Photograph: Family photo

Their children, Mia, Leo, Colin, and Laurent also gazed at the deep, inky darkness of the sky, awestruck.

Three of those children will lose their eyesight in the coming years, making the experience all the more important for Lemay and Pelletier, who plan to travel for the next year to give the kids as many visually rich experiences as they can.

“I want their heads to be full of beautiful landscapes that they can remember years from now,” she said.

Mia, 11, Colin, six, and Laurent, four, were recently diagnosed with retinitis pigmentosa, a rare degenerative

disorder whereby the cells of the retina gradually break down.

The loss of vision is expected to accelerate in the coming years, probably leaving them only a narrow sliver of sight by their 30s or 40s.

“There’s no cure,” said Lemay. “So, it’s a waiting game and there’s nothing we can do.”

Even though neither parent has blindness in their immediate family, both are carriers of the recessive genetic mutation responsible for retinitis pigmentosa.

Lemay and Pelletier’s firstborn, Mia, was diagnosed with the disorder after she had difficulty seeing objects at night, a hallmark sign. Colin and Laurent also had trouble seeing objects at night as infants, but Leo hasn’t been tested because he shows no problems with his vision.

As they digested the news that three of their children would become blind, the family initially tried to get Mia to learn braille. But in a cruel irony, her eyesight at the time was too strong.

Still, knowing that her vision would deteriorate, a specialist at the school suggested immersing the children in rich, detailed scenes.

“She said to show them giraffes and elephants. She meant books, but we figured why not just see the real thing?” said Lemay. “We’ve travelled with them before and they’re great on the road.”

Lemay, who works as a project manager, and Pelletier, who works in finance, had once dreamed of such a trip and had been saving for years to make it happen.

The family flew from Montreal, Quebec, nearly two weeks ago after their initial plans for a globe-spanning trip were delayed by the coronavirus pandemic.

Already, they have camped in the desert, sand-boarded and spotted Cape fur seals basking on the Atlantic coast.

After Namibia, they plan to travel the 1,100-mile Tazara railway from Zambia to Tanzania, where they will finally get the chance to see the big game animals most North American children only see in books.

If geopolitical tensions ease, they could be in Turkey and then Mongolia by late summer.

Lemay says she’s taken as many pictures as possible



Edith Lemay: 'I want their heads to be full of beautiful landscapes that they can remember years from now.' Photograph: Family photo

to ensure even when her children have lost most of their sight, they still have something to look back on.

“Maybe they’ll be able to look at the photographs and the pictures will bring back those stories, those memories, of the family together.”

The trip, like any foray into a new place, has also proven exhausting, as the parents juggle logistics, planning with the realities of homeschooling four children on the road. Lemay and Pelletier are documenting their travels, and occasional frustrations, on their page, *Le monde plein leurs yeux*.

Despite moments of friction, brought on by hunger, tiredness or the realities of corralling four energetic youth, Lemay says the trip has already left her with the memories she had hoped for.

Earlier in the day, as they drove along the western coastline of the sub-Saharan nation, the family stopped to visit a famous shipwreck.

“They just asked to dip their toes in the ocean,” said Lemay. “But with kids, it’s never just the toes. Five minutes later they’re soaking wet and soon there’s sand and water in the car. But they’re just so excited.”

Dan Parker, a Blind Man, Breaks Driving Speed Record

Via the National Federation of the Blind PR Newswire

Dan Parker, a blind racecar driver, achieved the GUINNESS WORLD RECORDS® title for the “Fastest Speed for a Car Driven Blindfolded” on Thursday, March 31, 2022. Parker set a new speed record of 211.043 miles per hour on the runway at Spaceport America in his custom-built Corvette, which included an innovative audio guidance system designed to his specifications. The previous record was held by Mike Newman of the United Kingdom, who achieved a speed of 200.51 miles per hour in 2014.

Parker went blind as the result of a racing accident that took place ten years before, on March 31, 2012, and graduated from the Louisiana Center for the Blind seven years ago on March 31 as well. The record attempt was made as part of the acceleration of the National Federation of the Blind’s Blind Driver Challenge™ — an initiative



that aims to call attention to the importance of breaking barriers in mobility and to demonstrate the incredible achievements of blind people. It was sponsored by San Francisco-based zero emission self-driving company Cruise and certified by Guinness World Records official Michael Empric.

The effort built on the inaugural Blind Driver Challenge event that took place on January 29, 2011, when Mark Riccobono, now President of the National Federation of the Blind, independently operated a modified Ford Escape hybrid on the Daytona International Speedway Road Course. Mr. Riccobono navigated the course's turns and steered the car around dynamic obstacles by following haptic prompts generated by input from the vehicle's GPS, cameras, and LIDAR sensors.

"Our Daytona Blind Driver Challenge demonstration changed the perceptions of blindness held by society, including the perceptions that we ourselves held as blind people," said Mark Riccobono, President of the National Federation of the Blind. "It further demonstrated to the world that the expertise of the blind is critical to the development of nonvisual vehicle interfaces. NFB member Dan Parker has now raised the expectations

of blind people even higher by independently driving a vehicle faster than any blind person has done before, proving that the combination of accessible technology and our own capacity allows blind people to safely operate motor vehicles even at high speed. This demonstration reinforces our determination to work with Cruise and other partners to make cars that can be operated independently by blind people on America's roadways a reality. Transportation is a critical barrier faced by blind people across the nation and we seek the increased availability of all transportation options in order to successfully live the lives we want."

"With the help of my Federation family, my outstanding pit crew, and our partners at Cruise, I am proud to bring the GUINNESS WORLD RECORDS title for fastest speed for a car driven blindfolded to America," said Dan Parker. "We have not only demonstrated that a blind person can operate a vehicle safely, but that we can do it at over two hundred miles per hour. We hope this success inspires blind people and shows the world the potential of modern technology like self-driving cars to help the blind break barriers in everyday mobility and beyond."



We Couldn't Do It Without You

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

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

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

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

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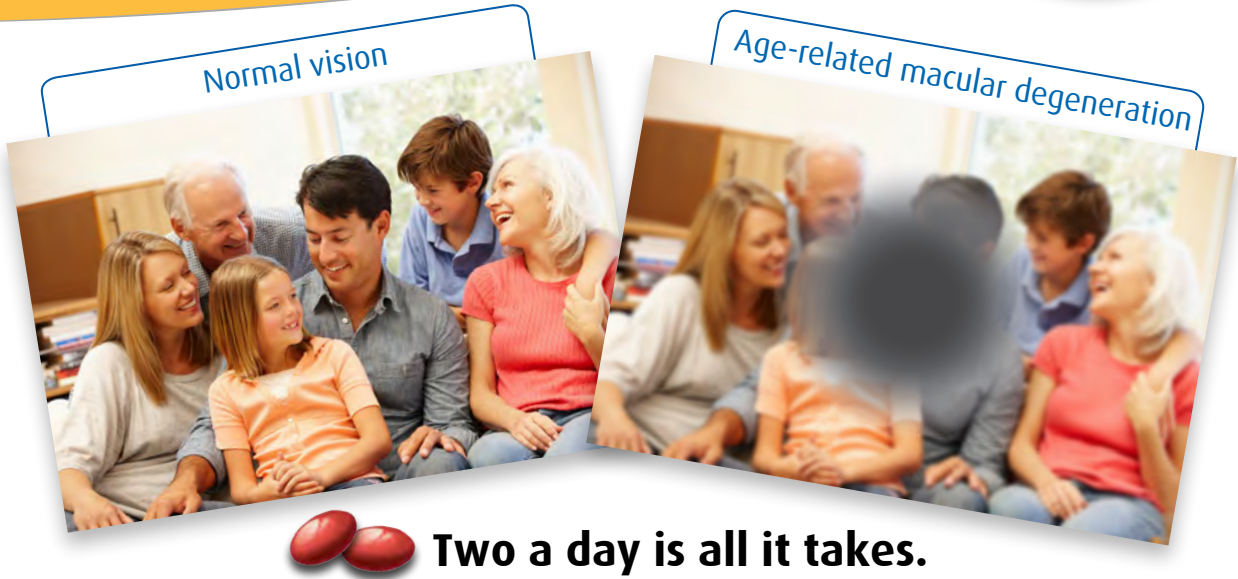


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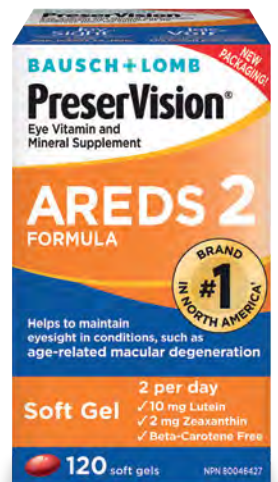
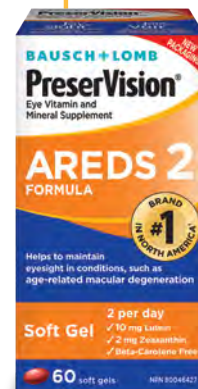
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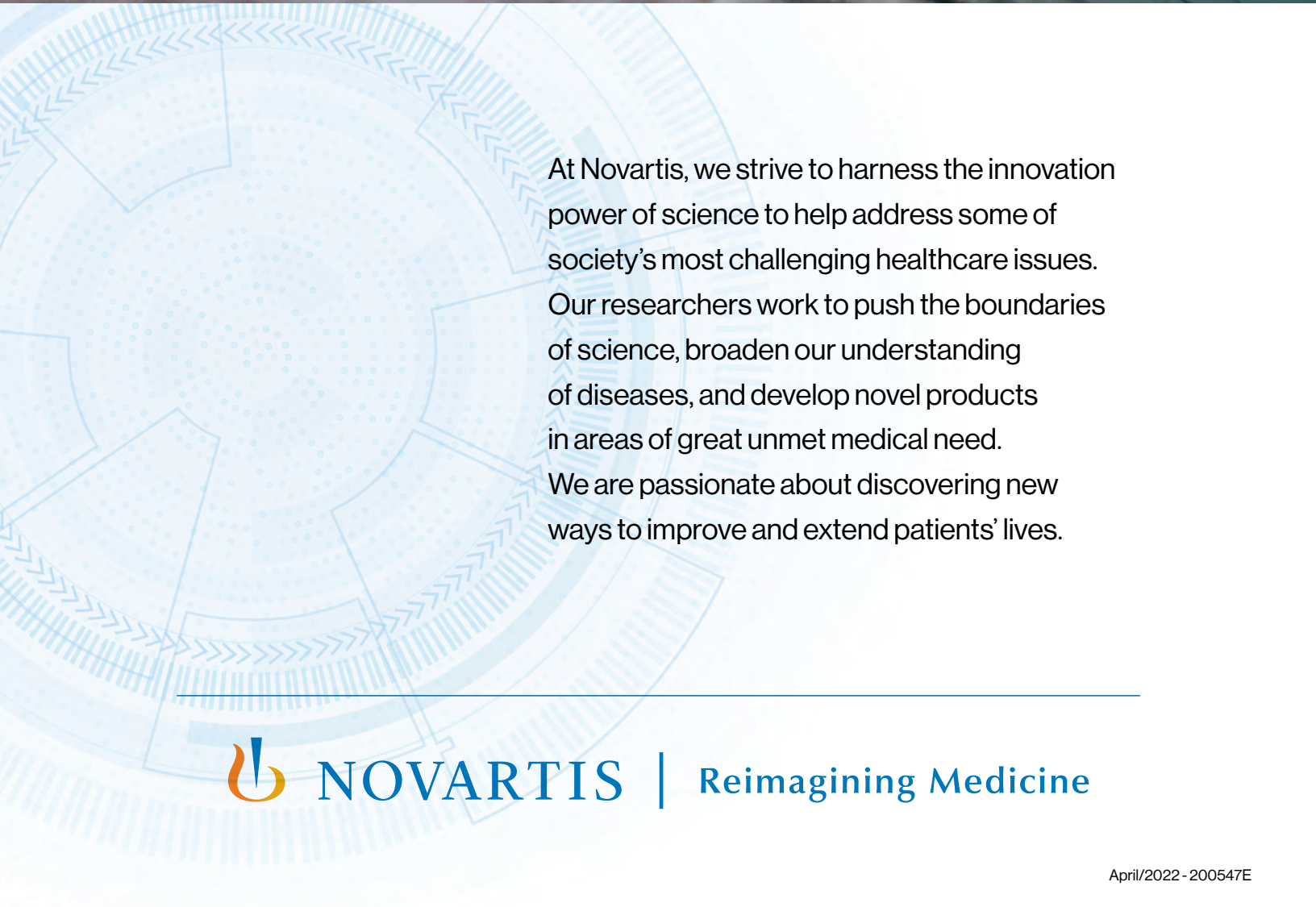
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At Novartis, we strive to harness the innovation power of science to help address some of society's most challenging healthcare issues. Our researchers work to push the boundaries of science, broaden our understanding of diseases, and develop novel products in areas of great unmet medical need. We are passionate about discovering new ways to improve and extend patients' lives.

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