

THE CANADIAN COUNCIL OF THE BLIND

WHITE CANE MAGAZINE MARCH 2022

# White Cane

*The Voice of the Blind in Canada™*

## Magazine

## Addressing Preventable Vision Loss



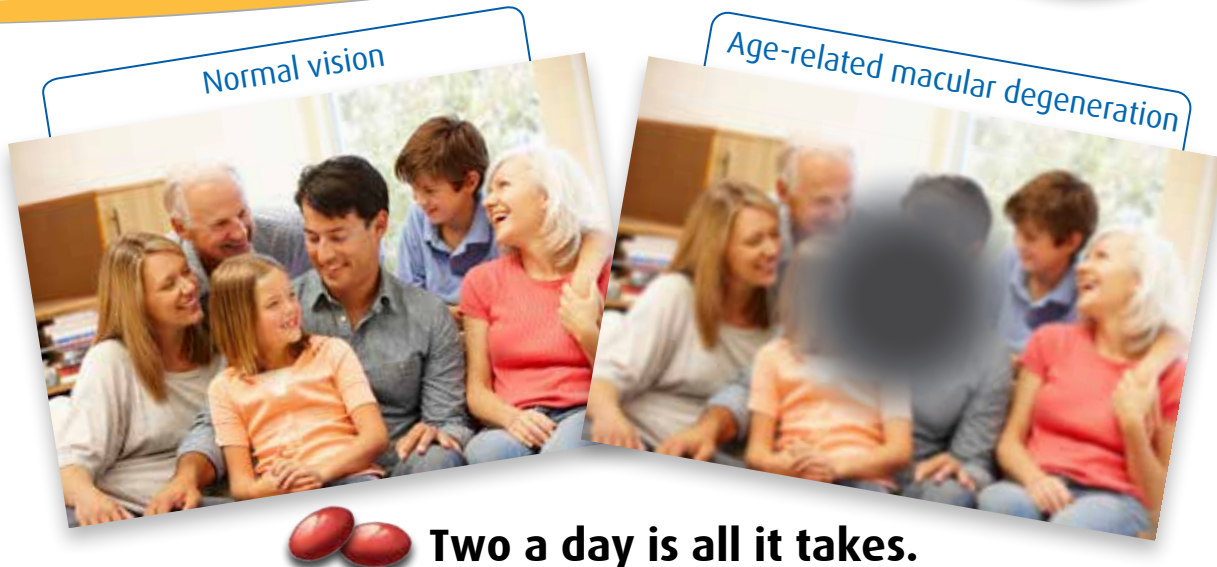
### INSIDE:

**Can Canada Course-Correct?  
Your Primary Eye Care Provider  
Failure to Deliver Costing Billions  
Ian's Story: A Sense of Self**

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CANADIAN COUNCIL  
OF THE BLIND



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# PRESIDENT'S MESSAGE

by Andre Martin



**“Today, we continue to move forward and play a larger role in advocacy, research, education and pharma”**

Since becoming President in mid-June of last year, I have endeavoured to lead the Canadian Council of the Blind (CCB) in the same positive direction that former President Louise Gillis was taking the organization.

It is essential for the CCB to remain at the forefront of issues and concerns that are vital to our membership. Additionally, I'm committed to ensuring the initiatives and goals undertaken by Louise Gillis are maintained and achieved and am working with the board to move forward effectively.

COVID-19 challenges and a return to normalcy remain at the forefront of our thoughts. We are expanding our vision health, advocacy, and educational efforts to reflect many of the realities and concerns the pandemic has imposed upon us.

The Council has restructured our committees and engaged our new board members to develop their knowledge and talents to reflect what is, and will be, our focus moving forward into next year and beyond.

Our exceptional staff and volunteers in the CCB Get Together with Technology program have continued their fine efforts in ensuring that cutting-edge technology is always available to facilitate meetings, peer support, and communication within our community.

The Council will continue to direct our energies towards working with the government to implement the Accessible Canada Act. I will continue our advocacy efforts ensuring that persons with vision loss are included as changes are made to the Act.

Today, we continue to move forward and play a larger role in advocacy, research, pharma, education and pharma, ensuring that individuals living with vision loss maintain their quality of life as we strive to break down barriers.

I look forward to working with the vision loss community alongside our wonderful sponsors, partners, donors, board and committee members, staff, and volunteers, all of whom are dedicated to keeping the CCB moving toward a bright future.

A handwritten signature in black ink, appearing to read 'Jim Tokos'.

Jim Tokos  
National President  
Canadian Council of the Blind

**The CCB Stands with Ukraine**  
**see page 45**



# REFLECTIONS ON 2021 AND MY SERVICE

by Andre Martin



**“We continue working to ensure that the Accessible Canada Act moves forward”**

Over the last number of years, the Canadian Council of the Blind (CCB) has worked collaboratively with its partners, supporters, sponsors, and other stakeholders to have a positive impact on Canada’s blind and low-vision community. This past year was no different, despite the impact of COVID-19. Together, we can “build back better”!

As we all know, the pandemic has made life more difficult for persons living with vision loss and has also negatively impacted sight loss prevention efforts. It’s with this knowledge that we sent a message to Health Canada advocating for persons with disabilities and particularly sight loss to be placed higher on the priority list to receive vaccines as they became available.

During White Cane Week, I was pleased to present the Person of the Year Award to Gerry Chevalier, who has been an amazing promoter and worker with the blind community. The 2021 President’s Award was presented to Doug Earle and Fighting Blindness Canada (FBC), which has been a major partner to the CCB in so many ways to improve the quality of life for those living with blindness and most importantly in the prevention of blindness.

The CCB was very active this year as we promoted our report on the Cost of Vision Loss and addendum report on the effect that the COVID-19 pandemic has had. These reports have been distributed widely to government and the public, and are available on our website. The report was made possible through the collaborative effort of the CCB, FBC, the Canadian Ophthalmological Society, and the Canadian Association of Optometrists along with Deloitte and our supporters. The reports were presented at our White Cane Summit and Gala as well as through a variety of media outlets. It was very rewarding to a part of this great accomplishment.

Through working with the CNIB and other organizations, we’ve contributed to Canadian efforts and progress toward accessible insulin pumps and accessible payment systems. Both these projects are still in the works. Moneris has developed a device with accessibility features that have been tested and recommendations have been put forward, so accessible payment systems are on the horizon for Canadians who need them.

As we continue working to ensure that the Accessible Canada Act moves forward, the CCB is represented at many of the varying committees to provide input so that regulations move ahead and exemptions are minimized, therefore enabling accessibility. The CCB also continues to have a strong presence on the Canadian Transportation Accessibility Advisory Committee to ensure that regulations are in place and exemptions are avoided, thus removing barriers for persons with disabilities.

Even though the pandemic has kept us at home, we’ve worked with pharmaceutical companies at the local and international level. These efforts enable people with lived experience to help identify better ways to produce therapies for eye care that are more accessible to persons with sight loss.

**“After nearly 11 years, it was time for change and to get new people more active in the organization.”**

Throughout the year, I’ve been actively involved with the World Blind Union and an active participant in the NA/C region I have been representing Canada on the Women’s committee. The committee has been looking at ways to increase involvement and leadership role for women in all countries but most importantly in developing regions. Following a recent survey to look at needs it was decided that WBU would develop an Empowerment Award to be presented to one of the women who could be nominated by their country to receive it. As one of the leaders in this project I along with two other women carried out this project and the presentation was made at the General Assembly. Due to COVID-19, unfortunately the General Assembly had to be held virtually with a relatively good attendance considering all time zone and three languages.

There are a number of organizations that I’ve worked with to represent the CCB this year, including: the Council of Canadians with Disabilities; Barrier Free Canada; the CNIB; Consumer Access Group; Best Medicines Coalition (BMC); committees on drug pricing, new drugs, and technology; government agencies; and pharmaceutical companies, to name a few. The CCB has been working with BMC to assist in creating the coalition’s policy principles on the creation of a federal strategy for rare drugs – treatment for rare eye conditions is included. Our work with the International Federation on Ageing continues to be very productive.

Our CCB Bylaw Committee has been working to totally review and bring the bylaw into line with the Canada Not-for-Profit Corporations Act. The new edition has been approved by our members and is registered with government. I want to thank all members on the committee for their commitment and success in bringing the CCB Bylaw up to date. All committees have been fully involved in the work needed to keep the Council moving forward in a positive manner. Therefore, I wish to thank everyone who took on this added work to ensure that the CCB will be around well into the future.

2021 was election year, which was held virtually at our AGM. I made the decision to not offer for the position of President again. After nearly 11 years, it was time for change and to get new people more active in the organization.

I’m pleased with the work we’ve done, and most particularly in the last three years. We’ve had a tremendous commitment from the Board as well as from our collaborators, partners, and supporters over this time, for which I am truly grateful. I wish the new Board and President Jim Tokos great success well into the future.

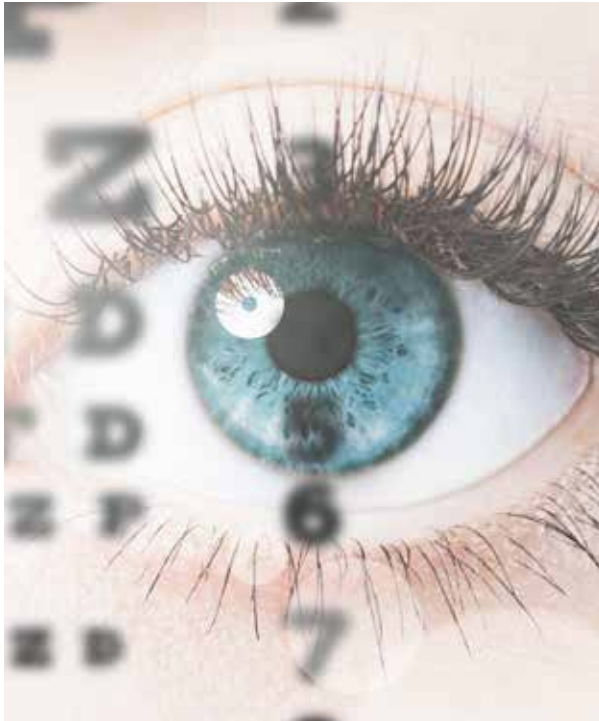
In the role of Past President, I will continue to be active in several areas. The main area for me is to be involved with eye health through assisting with CADTH submissions and working with organizations and pharma involved in the prevention of blindness. I will be advising the new president and Board of Directors as needed throughout this term.

The CCB and I personally is proud of the efforts to change what it means to be blind and of the leadership role in the vision loss community. Through our collaborations and independent work, we have played a key role in attaining relevant legislation, services, and appropriate eye disease treatments.



Louise Gillis  
Past National President, Canadian Council of the Blind

# 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](http://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.

## Editorial

# We Are Stronger Together: The Importance of Collaboration Among Organizations

by Andre Martin



No matter what your views are, most of us can agree that society is better when we work together. Canadians demonstrate this idea time and time again, when we come together and overcome an experience such as a natural disaster – neighbours collaborate to help neighbours, and it is through this teamwork that we persevere.

The same can be said in the not-for-profit domain. Charitable organizations face many obstacles, however, when we collaborate with partners, we become stronger and can work smarter and more efficiently.

Central to the concept of collaboration is the continuing independence of each organization while finding the ways and means to collaborate where it is in the best interest of the community and the organizations themselves. With the will to succeed and the awareness that the challenge is to respond to a need for support to individuals at a critical time in their lives, organizations can create an effective working model of collaboration.

The Canadian Council of the Blind (CCB) knows this to be true, and we have been working and partnering with other organizations and stakeholders for many years in order to strengthen our capacity to support blind and low-vision Canadians.

Over the years, the CCB has worked with all levels of government to provide direction and encourage health care initiatives that improve quality of life and support independence.

Our collaborators are as diverse as our members, and include such partners as Fighting Blindness Canada, the CNIB, VIA Rail, Lions Clubs, and the Royal Canadian Legion branches, as well as prominent advocacy groups like the Accessibility for Ontarians with Disabilities Act (AODA) Alliance. In addition, our collaborative efforts don't stop within Canada, as the CCB has two voting delegates from Canada on the World Blind Union's North America and Caribbean region and has worked with organizations such as the American Council of the Blind.

The goal of collaboration is to bring organizations together in a supportive environment to solve existing and emerging problems. While this may seem like a simple concept to grasp, it's not always as easy as it sounds. Collaboration is like any relationship – it takes hard work, dedication, compromise, and understanding in order to make it flourish.

The CCB is no exception. Our organization has had its share of bumps in the road collaborating with our partners. However, by always keeping our focus on what's important – the needs of the blind and low-vision community – we can rise above disagreements and reach our goals.

The CCB will always continue to work with community leaders and partners to promote awareness of issues faced by Canadians living with low vision and blindness. These partners have been integral to our growth and have played an important role in the expansion of our programs and public awareness campaigns such as White Cane Week.

Through these programs and others and along with a strong volunteer base, the CCB remains steadfast and 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 interests that all Canadians are able to contribute positively to their community and country.

Due to the lingering ramifications of COVID-19, White Cane Week will be different this year, but the spirit of the event remains the same. Please join me this year to continue to support our partners, peers, and community. Have a wonderful White Cane Week!

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

Mike Potvin  
Editor, 2022 White Cane Magazine

# Neovascular Age-Related Macular Degeneration and Its Associated Progressive Vision Loss Cannot be Reversed but It Can be Treated

Knowing your options and persisting with treatment is key

Laura Tennant, Postmedia Content Works

Age-related macular degeneration (AMD) is a disease that can lead to progressive loss of central vision. It was estimated that in 2019 more than 2.5 million Canadians were living with AMD, the leading cause of vision loss in people over the age of 50. There are two types of AMD – “dry” AMD, which is more common, and “wet” or neovascular AMD (nAMD). While nAMD represents only 10 to 20 per cent of all AMD cases, it is generally the most severe form of AMD and is responsible for 90 per cent of vision loss associated with this disease.

“The thing that takes people’s vision away, by and large, is the growth of abnormal blood vessels underneath the central part of the retina,” explains Dr. Peter Kertes, MD, ophthalmologist and retinal specialist at Sunnybrook Health Sciences Centre in Toronto. “These vessels may leak blood or other fluids, ultimately resulting in scarring of the macula, the central area of the retina.”

Although nAMD cannot be cured, it is treatable. Treatment consists of injections into the eye at regular intervals to help reduce the growth of abnormal or new blood vessels. “It may sound terrible, but, in truth, most patients tolerate it pretty well,” Dr. Kertes says.

The frequency of injections depends on each patient, their disease activity, and the therapy used.

However, studies have noted that fear and anxiety related to the method of administration and long travel times to appointments for those living in remote locations, are just some of the reasons why, over time many patients miss or discontinue treatment altogether. Some patients must be driven to their appointments, which can mean asking a caregiver to take a day off work, the doctor explains. Others may be managing multiple health conditions, adding to the challenge.

Despite these challenges, it is important to stay the course and persist with regular treatment. An American study observed that missing a single ophthalmology appointment over a two-year period was associated with decreased clarity or sharpness of vision for patients with nAMD.

Vision loss can have a profound impact on a person’s life, both financially and from a quality-of-life standpoint.





“It’s tough for patients with vision loss,” Dr. Kertes says. “As they lose their vision, they become more and more reliant on others.”

People living with vision loss may lose the independence associated with driving a car, and struggle to read and watch TV.

Doug Earle is the president and CEO of Fighting Blindness Canada, Canada’s leading charitable funder of vision research. Like Dr. Kertes, Mr. Earle wants Canadians to know about the significant impact that vision loss can have on a person’s well-being.

The recent Cost of Vision Loss and Blindness in Canada report revealed an important message. “There is an emerging crisis of preventable blindness,” Mr. Earle says. Over 8 million Canadians have vision-threatening eye diseases, with 1.2 million living with vision loss already.

It may be surprising to learn how many people are affected by vision loss. “Blindness can be invisible, you don’t recognize vision loss easily until it’s too late. These people are not seen through a regular eye exam [in the community],” Mr. Earle explains. This growing prevalence of vision loss in the country is concerning, as these numbers are only expected to increase.

With early diagnosis and regular treatment, people living with nAMD have greater chances to stop or reduce the slow leakage from the blood vessels which causes vision deterioration. Discussing your options with your ophthalmologist or retinal specialist is important to find a treatment that is right for you.

***If you or your loved one are living with nAMD, speak to your ophthalmologist or retinal specialist to determine which option may be right for you.***

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# POST PANDEMIC PERSPECTIVE: CAN CANADA COURSE- CORRECT AND PRIORITIZE PATIENTS?

BY DR. JANE BARRATT

We've heard about 'shadow pandemics' multiplying at unfathomable rates, touching nearly every aspect of our health, mind and body. Escalating crises in their own right, we need to ask ourselves some important questions, in order to chart a path forward, acknowledging all of the 'cracks' in the health system in our post-pandemic world.

Dialogue is always important, especially when advocating for ourselves, in health. Policy may seem far from the front lines of the pandemic, when in fact, it is exactly where decisions can be viewed through the equity lens, based on data and good practice to improve health outcomes across all ages.

Witnessed before our eyes, the last two years demonstrated just how fragile our healthcare system is, while clearly showing us where we need to focus from a policy perspective, to impact change. Older Canadians are disproportionately impacted and suffer the consequences of policies that need to be examined and drafted to meet

the needs of society today, not half a century ago. As Canadians managed their best to protect each other's health and get through the last two years, provincial governments have been busy at work trying to maximize health budgets, and with escalating healthcare issues daily, this presents a number of potential challenges for patients, and civil society.

If you live in Quebec for example, under a new health policy, patients will experience a switching period that starts in April of this year from their current treatment, to a biosimilar version. According to Biosimilars Canada, one of the main drivers for a policy such as this is to 'find cost savings for innovation', or is it really about helping to manage the exponential health expenditures every province is facing. Sounds like a fantastic way to save and still provide care, right? The answer isn't that easy and every Canadian should be looking at the 'fine print'.

*Continued on page 14*

# 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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CANADA

CANADIAN COUNCIL  
OF THE BLIND



LE CONSEIL CANADIEN  
DES AVEUGLES

**Scan the Code.  
Read the Report.  
Sign the Petition.  
Spread the Word.**

[stopvisionloss.ca](http://stopvisionloss.ca)





*Continue from page 12*

For many medications that Canadians need, biosimilars can be a good option to consider, but that is not always the case. If we look at the Quebec policy, a patient who has previously had treatment success on therapy and is mandated to switch to a biosimilar, would not be permitted to switch back to the original medication if there were any differences in efficacy. This policy does however, present some real and unique challenges in regard to the rights of patients in the safe and effective management of their condition.

Vision health is an area that will be impacted in the example of the Quebec policy, although unlike other therapeutic areas, a loss in efficacy means a loss in sight, and there is no guarantee that can be restored. Oncology is an example that presents a similar health challenge with the need for physicians to treat with the most aggressive and efficacious agent first. This would be problematic if they were restricted entirely, how can they provide the best care for their patient? They simply cannot. All cancer treatments are not openly accessible, but oncologists do have choice to treat, this is a distinction in the Quebec policy. The vision health community needs to prepare for impending policies across Canada that will only further restrict patient and physician choice.

Post-pandemic life should anticipate patient needs and challenges, and although only a small 'shadow' in the pandemic now, these looming policies will have negative consequences for future generations. The International Federation in Ageing (IFA) and allied partners continue to provide perspectives on issues affecting Canadians on matters related to vision health. Visit [www.EyeSeeYou.care](http://www.EyeSeeYou.care) for more information on biosimilar policies in your province, or to become an advocate for patient's rights in vision health.

<https://biosimilarscanada.ca/blog/biosimilars-canada-welcomes-the-implementation-of-quebecs-biosimilar-policy/>



Advocating for  
Options in  
Vision Health.

[www.eyeseeyou.care](http://www.eyeseeyou.care)

# AMI Year in Review: Highlights from the Year and a Preview of What's to Come



Dish with Mary host Mary Mammoliti

Like it was in 2020, the year 2021 was filled with uncertainty and fear because of the pandemic. COVID-19 affected Accessible Media Inc. (AMI) as well, necessitating working from home and strict safety protocols in the workplace.

But the pandemic didn't hinder AMI from launching exciting initiatives and celebrations throughout the year, including our first-ever AMI Connect virtual event.

Taking place in June, the virtual AMI Connect event introduced attendees to the stars of AMI's programs, including NOW with Dave Brown, Kelly and Company, AMI This Week, Level Playing Field, Kitchen Confession, Employable Me, and more. Attendees chatted with our

hosts and received tips and advice on everything from employment and assistive technology to making your kitchen a safe cooking space. They also learned more about our podcasts, how to access AMI in their area, and how we're serving members of the blind and partially-sighted community in Canada. Stay tuned for more information on this year's virtual event.

In July, we debuted Beyond the Field on AMI-tv, which examined important issues impacting the world of sport, specifically parasport. Hosts — and Paralympians — Greg Westlake and Travis Murao raised awareness and pushed the conversation forward through discussions with elite para-athletes, experts, and coaches. Beyond



**Kelly and Company co-hosts Ramya Amuthan and Kelly MacDonald**

the Field was the perfect lead-in to AMI's broadcast of the Tokyo 2020 Paralympic Games, in partnership with CBC, with live described video for audience members in the blind or partially-sighted community.

In September, AMI-tv debuted Dish with Mary, starring Mary Mammoliti. No stranger to AMI audiences, Mary appears on AMI-audio's Kelly and Company and AMI-tv's AMI This Week, and hosts the Kitchen Confession podcast. Each episode of Dish with Mary focused on one chef and one dish, plus a lot of laughs, a bunch of tips, and tons to dish about. A second season is in the works.

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

Things were just as busy on AMI-audio in 2021. In addition to live broadcasts of NOW with Dave Brown and Kelly and Company, we debuted two new reading programs. The Globe and Mail Today, with Mike Ross and

Corinne Van Dusen, delivers news, editorials and business, sports, and entertainment stories pulled from the latest edition of The Globe and Mail and read live, while Maclean's Magazine features host Matt Speirs reading a selection of feature articles from the most recent edition of Maclean's. These new programs complemented new episodes of The Pulse and The Neutral Zone.

AMI-audio extended its podcast reach with new series that included AMI Audiobook Review, about great new content in the audiobook realm; Connecting Disability, with host Meagan Gillmore and guests considering how experiences of disability help us connect with others and society; My Life in Books with Red Széll, featuring one-on-one interviews with authors who discuss their life, works, and three books that have resonated with them; and Triple Vision — in partnership with the Alliance for Equality of Blind Canadians — which tells the history of Canadians who are blind, deaf-blind, and partially-sighted one story at a time, illuminating the challenges of the past, present, and future. These new programs join established AMI-audio podcasts Kitchen Confession, Accessing Art with Amy, The Blind Reality, Low Vision Moments, Into You, Outdoors with Lawrence Gunther, and Tales from the Halifax School for the Blind.

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

Looking ahead to 2022, things continue to be busy for AMI-audio, AMI-tv, and AMI-télé.



**Ardra Shephard (centre) and the cast of Fashion Dis**





### By Hook or By Cook host Bruce Cook

New seasons of *Level Playing Field*, *By Hook or By Cook*, *Dish with Mary*, *#IGotThis*, and *Our Community* as well as new episodes of *AMI This Week*, *Double Tap TV*, and original documentaries are scheduled for AMI-tv. New series include *Fashion Dis*, hosted by Ardra Shephard. Debuting February 9 on AMI, *Fashion Dis* features the head-to-toe overhaul of a frustrated style-seeker discouraged by an industry that lacks adaptive options. We're proud to bring this long-overdue program to our audience. Additional new AMI-tv series include *Adaptable Animals*, which looks at the world of animals with disabilities and the advances in veterinary medicine that provide them with prosthetics; *Breaking Character*, which explores disability representation through the eyes of six performers trying to make it onto the screen, stage, comedy club circuit, and fashion runway; *In Focus*, a conversation with members of the disability community and the issues that are important to them; and *We Are One*, where we meet Canadian families — including members of the disability community — as they share stories of adapting, growing, and supporting each other. And, later this year, two beloved members of the AMI family will be headed to the small screen.

AMI-télé's programming is equally engaging. Several original programs are focused on entertaining, informing, and empowering the community we serve. Through informative weekly shows such as *Ça me regarde* and *Des familles comme les autres*, popular documentary series like cooking show *Pas de panique, on cuisine!* and renovation program *Pas plus compliqué que ça*, the hosts and collaborators all share knowledge and give advice, tips, and important information to the community.

2021 kicked off with the third season of hit series *Ça ne se demande pas*, a ground-breaking program that breaks down various societal taboos around disabilities. Participants answered questions most people want to, but don't dare, ask. A fourth season launched on January 17. In the fall of 2021, the documentary series *Viens souper* — hosted by Dominic Tardif — invited guests to share in discussions about a unifying topic, an opportunity to go beyond conversations about disability and talk about what excites them and makes them who they are today. A new show, *Mon guide yoga*, was added to AMI-télé's 2021 broadcast schedule, with host Andréanne Fortin expertly guiding her audience through stress-free sessions about better mobility and posture.



#### **We Are One's Claudine Santos, William Santos, and Adam McLaren**

The upcoming year brings an array of new original shows to AMI-télé, such as *Sept pieds sur terre*, which focuses on Canadians who are exceedingly tall; *Voir la musique autrement*, featuring accomplished world-known artists around the globe who share their stories and music; and *100% passion*, where common passions are at the centre of discussions.

[We Are One William at Splash Pad: We Are One's Claudine Santos, William Santos, and Adam McLaren]

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.

AMI's vision is to establish and support a voice for Canadians with disabilities, representing their interests, concerns, and values through accessible media, reflection, and portrayal.

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](http://AMI.ca) or [AMItel.ca](http://AMItel.ca) or email [info@ami.ca](mailto:info@ami.ca) to learn more about us.

As a longtime supporter and partner, AMI is proud to have participated in White Cane Week 2022.

All images are courtesy of AMI.



*Due to the pandemic and COVID -19 restrictions it was necessary to cancel our 2022 AMI Canadian Vision Impaired Curling Championship. We look forward to its return to the Ottawa Curling Club, from February 6-10, during White Cane Week 2023.*

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# A Call to Action: Saving Planet Earth Depends on Your Visualization and Storytelling Gifts

*BY LAWRENCE GUNTHER EUTENEIER*

Over the past year I've been issuing calls to action directed toward youth and others living with low or no vision. It began with a new podcast I started in September 2022 called *Outdoors with Lawrence Gunther*. Together with my daughter, who is now 15, we have attempted to inspire other blind and low vision people to connect with nature in fun, meaningful, and sustainable ways. At the same time, we've endeavored to inform our listeners to apply their visualization and storytelling skills to speak out on behalf of nature. I wasn't sure if the call would be heard, but with the support of Accessible Media Inc. and with nature needing to be heard more than ever, it was time.

I'm fortunate to have grown up with the outdoors being a huge contributor to my development. It started at our cottage located on 100 hectares of forest complete with a pond. This led to five years as a member of Scouts Canada spent mostly canoe camping and river racing, and a voyage in 1977 that started at the mouth of the Credit River just west of Toronto and ended on Cabot Beach

in P.E.I. just in time for the Canadian Scout Jamboree. Even though I attended a public high school in spite of being registered blind at age eight, I never excelled playing team sports in spite of two years on the high school football team, and preferred instead to explore the forests and rivers that surrounded my hometown of Georgetown. Camping, fishing, and even hunting, my friends and I enjoyed the outdoors year-round.

Having to move to Toronto to attend college and then university represented a huge change in my life. It was during these nine years I spent pursuing post-secondary education that my diminishing eyesight reached a point that I became functionally blind. I had to do something, and in 1986 I was trained with my first guide dog. The CNIB taught me braille, and in 1988 my university installed a talking computer in their library just in time for me to write my undergraduate thesis.

While pursuing my master's in environmental studies I conducted field research with the support of various



granting agencies. I was able to document First Nations issues specific to Alberta's dam construction program along the eastern slopes of the Rockies, and to reside in Inuvik, N.W.T., for three months to meet and learn from blind Native and Inuit knowledge keepers and storytellers. My summers were spent in a cabin in Cape Breton, where I worked for local artisanal cod and lobster fishers aboard their homemade wooden dories up until the collapse of the cod fishery in 1992. My last year of studies involved relocating to northern Sweden for a year as a guest researcher and lecturer with Umeå University.

My commitment and connection to nature remains strong, and over the years I've produced numerous documentaries, short videos, podcasts, blogs, articles, and plenty of TV content. It's earned me the Governor General's Meritorious Service Medal, the Public Service Award of Excellence, and numerous other awards and recognitions.

Having encountered all manner of access barriers over the years, I've also felt compelled to take on accessibility issues – otherwise, much of what I do wouldn't be possible. This included initiating and managing the Web Accessibility Office at Industry Canada where we



conceived and funded development of the Web-4-All technology and the Access-4-All software that's now imbedded in all Apple products. Even though much work remains on the accessibility front, my call to action has little to do with removing barriers, and focusses mainly on the unique strengths of people who live with vision loss.

For many thousands of years, people with vision loss served their communities as knowledge keepers and storytellers. I'm privileged to have met a number of elder blind Inuit and First Nations people who have dedicated their lives to continuing this tradition. And even though many other modern forms of information storage and sharing now exist, their services are still highly regarded within their communities.



Blind knowledge keepers and storytellers must first commit to memorizing legends passed down for thousands of years. They must also tell these stories in ways that transport their listeners back in time. People who live without the ability to see have an advantage in that we become highly skilled at visualizing the world around us.

My goal in reaching out to others living with vision loss is two-part. The first entails passing on the skills and motivation to form their own personal connections with nature. The second is to challenge these people to become a voice for nature so others might understand how our lifestyles and choices are negatively impacting nature. This is especially the case for what's taking place out of sight beneath the surface of our rivers, lakes, and oceans.

More than ever our planet needs to be heard. It needs people to speak up on its behalf. By sharing traditional, local and scientific knowledge through storytelling, people are able to open their minds and imaginations to where we have come so that we might one day find our way back to living in harmony with nature.

To get involved or support me in this work, there are several options. The charity I founded in 2012, Blue Fish Canada, can provide you with a wide variety of resources that make use of the latest mediums to inform and inspire others. You can also arrange to have me speak to your organization or at your place of work, either in person or virtually. If you want to become a storyteller yourself, even better – the world needs more people skilled at describing through stories what's taking place outside our cities so the rest of society will make sure our politicians get the message that the earth comes first.

*To learn more about the charity Blue Fish Canada visit:*  
[www.BlueFishCanada.ca](http://www.BlueFishCanada.ca)

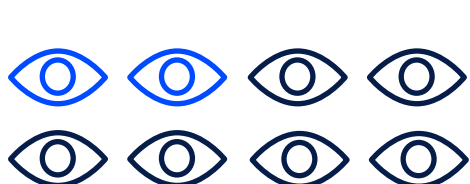
*For more about the Outdoors with Lawrence Gunther podcast and to read my blog visit:*  
[www.LawrenceGunther.com](http://www.LawrenceGunther.com)

# GLAUCOMA IMPACT IN CANADA: NATIONAL SURVEY

**Glaucoma** is an eye disease where increased eye pressure can damage the optic nerve.<sup>i</sup> It is one of the leading causes of blindness in Canada.<sup>ii</sup> Today, over 728,000 Canadians are impacted by glaucoma.<sup>iii</sup>

**Glaucoma signs and symptoms:** Glaucoma can develop in one or both eyes, and in most forms of the disease there are no early symptoms that can be self-detected.<sup>iv</sup>

## A RECENT SURVEY OF 684 CANADIANS AGED 50 AND OVER REVEALS:



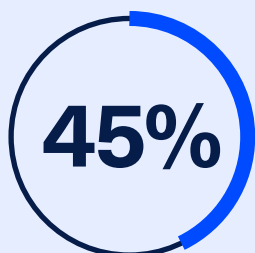
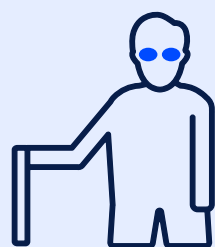
**1/4 OF CANADIANS 50+**

surveyed have experienced **VISION STRAIN**  
from **INCREASED SCREEN TIME**  
within the last **18 MONTHS**.

**ALBERTANS,  
ONTARIANS, QUEBECERS,  
and ATLANTIC CANADIANS**

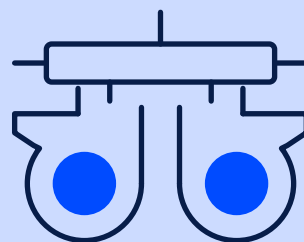
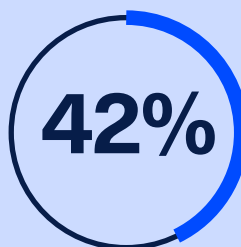
are significantly more likely to say they **SUFFERED VISION STRAIN**  
from extra time on computer monitors, smart phones, e-readers, TV, etc.

**COMPARED TO THOSE IN THE PRAIRIES.**



of **CANADIANS 50+**

do not know **GLAUCOMA** is the  
**LEADING CAUSE OF  
BLINDNESS.**



of **CANADIANS 50+**

have not seen an **OPTOMETRIST**  
within **THE LAST 18 MONTHS.**

### Survey Methodology:

Online survey of 684 Canadians aged 50 and over was completed between Sept. 10-12, 2021, using Leger's online panel.  
The estimated margin of error is  $\pm 3.75\%$ , 19 times out of 20.

<sup>i</sup> Fighting Blindness Canada. About Glaucoma. Retrieved from [https://www.fightingblindness.ca/wp-content/uploads/2021/03/FBC\\_OnePager\\_Glaucoma.pdf](https://www.fightingblindness.ca/wp-content/uploads/2021/03/FBC_OnePager_Glaucoma.pdf). Accessed October 1, 2021.

<sup>ii</sup> Canadian Association of Optometrists. About Glaucoma. Retrieved from <https://opto.ca/health-library/about-glaucoma>. Accessed October 1, 2021.

<sup>iii</sup> Fighting Blindness Canada. About Glaucoma. Retrieved from <https://www.fightingblindness.ca/eyehealth/eye-diseases/glaucoma/>. Accessed October 1, 2021.

<sup>iv</sup> Fighting Blindness Canada. About Glaucoma. Retrieved from <https://www.fightingblindness.ca/eyehealth/eye-diseases/glaucoma/>. Accessed October 1, 2021.

# Addressing Preventable Vision Loss

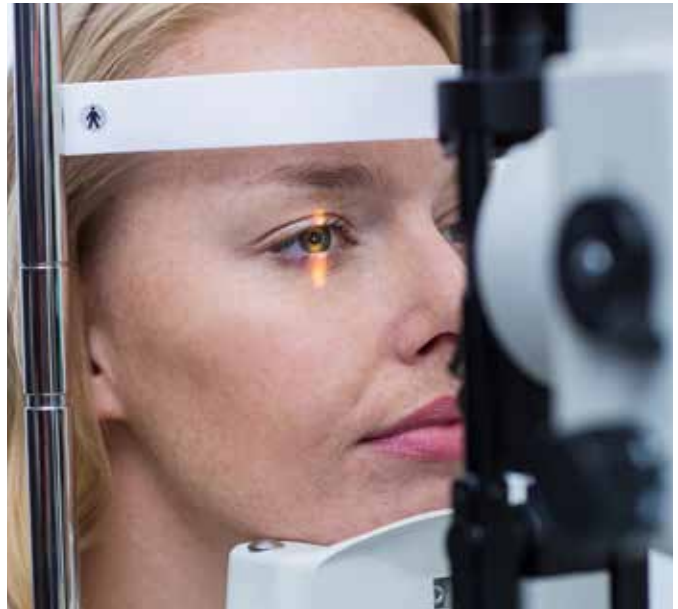
BY DR. MARKO M. POPOVIC

Over 8 million Canadians live with four major blinding eye conditions: age-related macular degeneration, cataracts, glaucoma, and diabetic retinopathy. Approximately 1 in 5 Canadians are affected by one of these conditions. At the same time, 75% of vision loss is preventable or treatable, and preventable blindness costs \$32.9 billion annually in Canada.<sup>1</sup>

Preventing the progression of chronic eye conditions is essential for the overall health and quality of life of our citizens. How can we improve our efforts to prevent blindness? Ocular screening is the key.

Major screening programs, such as for breast cancer and colon cancer, are publicly funded and start at age 50. In eye care, the Ontario government only funds eye examinations after age 65. Why should eye care be any different? In our experience, Ontarians aged 50-64 are being affected by blinding eye conditions and are routinely avoiding eye exams because of costly out-of-pocket exam fees and lack of private insurance. All too often, individuals present to their eye care provider after 65, at which point it may be too late to intervene for advanced cases. Successful treatment of many eye diseases depends on their early diagnosis and treatment. Detection of these diseases in their earliest stages will undoubtedly also reduce the costs associated with their treatment in the long term while also reducing the most severe vision loss and improving the quality of life of those living with these diseases.

The Canadian Council of the Blind, Fighting Blindness Canada, and the Department of Ophthalmology and Vision Sciences of the University of Toronto have partnered to design a new landmark study to evaluate this problem. In this study, we aim to provide evidence for the burden of common eye conditions in individuals aged 50-64. We aim to use a rigorous analysis approach in which we sample Ontarians at random that are aged 50 and over and compare the prevalence of eye conditions between those aged 50-64 and 65 and over. We aim to recruit thousands of Ontarians across the province to undergo eye exams to assess for conditions such as age-related macular degeneration, cataracts, glaucoma, and diabetic retinopathy. Eye exams will take place at optometrist offices, Ontario Seniors Active



Living Centres, or in a mobile eye clinic provided by the Canadian Council of the Blind. We will examine not only the prevalence of these conditions, but the barriers that those aged 50-64 face in accessing eye care, as well as the impact of these eye conditions on their quality of life. To further prove that routine eye exams should be publicly funded in this age group, we aim to do a cost effectiveness analysis to show that ocular screening is a cost-effective intervention, starting at age 50.

Currently, too many Canadians experience unnecessary vision loss each and every year. By donating to the Canadian Council of the Blind or Fighting Blindness Canada, you will make a difference and join us to help stop preventable vision loss.

## REFERENCES

1. Gordon KD. Canadian Council of the Blind's, Summary Report on the Cost of Vision Loss and Blindness in Canada. Deloitte Access Economics; 2021. Available at: <https://www.fightingblindness.ca/wp-content/uploads/2021/05/Deloitte-Final-Acc-of-VL-and-Blindness-in-Canada-May-2021.pdf>

Note: Marko M. Popovic MD MPH (C) Department of Ophthalmology and Vision Sciences, Faculty of Medicine, University of Toronto

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Chapter  
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\*Name Update  
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**For more information about the CCB or to  
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# Optometrists: your primary eye care provider



Optometrists are to your eyes what a family doctor is to the rest of your body – the “front line” for your vision health. As primary eye care providers, optometrists provide a wide range of care and treatment and are often the first eye health professionals that patients see, from infants, children in school, adults, and seniors. There are more than 6000 optometrists across Canada, located in almost every community. While the vast majority of them provide care in a private practice, they also work in clinics, community health centres, hospitals, and academia.

An optometrist diagnoses, treats and helps prevent diseases and disorders affecting the visual system, the eye and related structures. Many serious eye conditions – glaucoma, cataracts, macular degeneration - don't have obvious symptoms, with some only showing symptoms when the condition is advanced and difficult, or even impossible, to treat. Interestingly, because of the eye's small nerves and blood vessels, delicate structures, and close proximity to your brain, an optometrist can also identify symptoms of conditions elsewhere in the body like high blood pressure and diabetes. All of this assessment can be accomplished during a comprehensive eye exam, making it one of the least invasive steps you can take to protect your overall health.

During the exam, optometrists evaluate a variety of factors that can affect your vision and eye health. This includes reviewing a patient's case history, conducting an external and internal exam of your eyes, and measuring vision qualities, such as eye movements and coordination, sharpness of vision and peripheral vision. They also evaluate your ability to adjust focus, and to see colour and depth normally. At the end of the

exam, an optometrist may recommend glasses, contact lenses, exercises, medication, or surgery. If surgery is recommended, an optometrist will make a referral to an ophthalmologist (eye specialist) on your behalf.

While the exam is, by virtue of its name, ‘comprehensive’, there are often questions about how frequently an exam is required. Established in 1948, the Canadian Association of Optometrists (CAO) is the national voice of optometry, providing leadership and support to its members to enhance the delivery of healthy eyes and clear vision for all Canadians. CAO examined the issue of periodic optometric examination and based on the clinical evidence, recommends that infants and toddlers should be examined at least once between six months to two years of age; once between 2-5 years of age, annually for children 6-19 years, every two years for adults and annually for seniors. An optometrist may recommend more frequent examinations depending on a patient's individual eye health.

Your vision is priceless. Routine comprehensive eye exams by an optometrist not only ensure good vision and eye health, but an enhanced quality of life. Find an optometrist near you and call for your appointment today.



CANADIAN ASSOCIATION OF OPTOMETRISTS  
ASSOCIATION CANADIENNE DES OPTOMÉTRISTES

# Reforming Ontario's Assistive Devices Program

*By Keith Gordon*



For over 30 years, Ontarians with vision loss (VL) have benefited from the Assistive Devices Program (ADP), an invaluable resource that partially funds some of the costs associated with essential assistive devices. The technology revolution has impacted the lives of people living with VL to such a dramatic degree that there are now very few activities that a person who is blind or partially-sighted cannot participate in when equipped with the appropriate technology. For this reason, the Canadian Council of the Blind (CCB) feels that it is essential that the ADP keep pace with changing technology and provide rapid reimbursement for assistive devices.

In response to reports from users of the ADP expressing frustration with various aspects of the ADP, the CCB, in collaboration with a group of stakeholder organizations – the Vision Loss ADP Reform Working Group – that represent Ontarians living with VL, undertook a survey of people living with VL to better understand their experiences with the ADP. The motivation for this report was further driven by the fact that in 2019/2020, only 6,000 people with VL received ADP funding out of a population of 466,000 Ontarians living with VL.

The Vision Loss ADP Reform Working Group felt very strongly that it is essential that people living with VL be consulted with respect to the reform of the delivery of the ADP if the program is to be of real benefit to Ontarians living with VL.

The primary goal of the survey was to develop a rigorous and client-centered evidence base from which to make recommendations to ADP governing bodies that are informed, substantive, and reflective of the needs of Ontarians living with VL.

The survey of people living with VL was conducted online by the CCB in November 2021 and received a very robust response, which enabled an in-depth analysis of responses of both people who had accessed the ADP over the previous five years, as well as those who had not accessed the program. We felt that it was just as important to understand why people had not accessed the program.

During the initial stages of the survey, we became aware of a number of issues that were being reported to us by ADP authorizers and vendors that warranted inclusion in this study. For this reason, we undertook a supplemental survey of ADP authorizers and vendors.

The results of both surveys along with a substantive set of recommendations were compiled in a 108-page report, which is available on the CCB website at: [www.ccbnational.net](http://www.ccbnational.net)

The key findings and recommendations have been presented to people in the Ontario Ministry of Health as well as the ADP management, all of whom have expressed a willingness to work collaboratively with people living with VL, and the appropriate stakeholder organizations, to effect the necessary changes to optimize this extremely worthwhile program.

The initial stakeholders represented in the Vision Loss ADP Reform Working Group, which is led by the Alliance for Equality of Blind Canadians (AEBC) Toronto Chapter, are the Canadian Council of the Blind (CCB) Toronto Visionaries Chapter, the CNIB Foundation, BALANCE for Blind Adults, Fighting Blindness Canada (FBC), the FBC Young Leaders Program, the CCB's Get Together with Technology (GTT) Program, and the Inclusive Design Research Centre (IDRC) at OCAD University.



# Canadian Ophthalmological Society

## Representing the leaders of your eye care team

The Canadian Ophthalmological Society (COS) ([www.cos-sco.ca](http://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

**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

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.



### RESOURCES FOR PATIENTS AND THE PUBLIC

*See the Possibilities ([www.seethepossibilities.ca](http://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.*



AN EYE ON THE FUTURE

# TODAY 95% OF AVOIDABLE BLINDNESS CAUSED BY DIABETES IS SOLVED WITH A CLICK<sup>1</sup>.

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"<sup>2</sup>, 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."<sup>3</sup>

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](https://www.youtube.com/watch?v=J8TRX9b_-il)  
3. <https://www.sedar.com/DisplayCompanyDocuments.do?lang=EN&issuerNo=00003037>



# Funding Research is Core to Fighting Blindness Canada

Fighting Blindness Canada (FBC) is the largest charitable funder of vision research in Canada. Over our 48-year history, FBC has contributed 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.

Over 8 million Canadians are living with a blinding eye disease (age-related macular degeneration, glaucoma, diabetic retinopathy, and cataracts) that puts them at significant risk of blindness.

Because of research, we can prevent 3 out of 4 cases of vision loss through early diagnosis and treatment. But there is still more to be done.

1.2 million Canadians are living with uncorrectable vision loss, and vision loss is estimated to grow by 67% to 2 million Canadians by 2050. Research is critical to prevent further vision loss and to restore sight.

Vision loss in Canada has an annual cost of \$32.9 billion. It has broad impacts on individuals and their families, including challenges with day-to-day activities, schooling, employment, and financial and mental health pressures.

This is why FBC continues to invest in sight-saving research. Research to improve diagnosis, to shed light on genetic causes of rare eye disease and to develop new and innovative treatments for the many Canadians

who do not have any treatments available. In 2020, the first gene replacement therapy for an inherited retinal disease was approved by Health Canada. And this is just the first one. Research is turning the promise of gene, stem cell, and optogenetic therapies into a reality.

We believe that, while it starts with research, it doesn't end there. FBC is committed to ensuring that once new and innovative treatments are developed, Canadians can benefit from them. While the gene therapy Luxturna was approved by Health Canada in 2020, Canadians still do not have access to it because it is not covered by provincial drug plans. FBC has been engaging and advocating for access because each day that goes by means less sight for individuals who are waiting to access Luxturna. We need your help to tell the government that Canadians deserve access to sight-saving treatments. Share your voice at [approvaluxturna.ca](https://approvaluxturna.ca).

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

*Learn more at [fightingblindness.ca](https://fightingblindness.ca)*



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# How Access to Innovative Medicines Can Change Lives

“Both of my children, 21-year-old Jenna and 17-year-old Adam, were born with retinitis pigmentosa, a genetic disorder that causes vision loss. They’re both doing great – Jenna is a vlogger with a successful YouTube channel and Adam is a second degree taekwondo black belt heading to university in the fall – but all their lives they’ve had to overcome a long list of barriers.

In some ways, my kids are just like every other young person – they act the same way, have the same attitude, and enjoy the same things as everyone else. But there’s an added layer. They access the world differently. Watching them navigate social interactions, develop friendships, and struggle with accommodation at school is hard for me as a parent. There are so many systemic barriers.

The latest barrier is getting access to sight-saving surgery. Jenna was able to participate in a U.S.-based RPE65 clinical trial 11 years ago that saved her sight in one eye. This trial helped build the case for an innovative sight-restoring treatment called Luxturna. Adam was too young to participate, and now the disease is progressing for Adam and in Jenna’s other eye. With Adam’s vision deteriorating, everyday things like reading and writing at school have become more challenging for him.

Health Canada recently approved Luxturna as a treatment that can be delivered in Canada. This targeted gene therapy can prevent blindness in people with inherited eye diseases, and my kids desperately need access to it. It’s here, it’s available, but it’s still out of reach. It’s going through a bureaucratic process that could take two years to determine if it will be a publicly-funded treatment.

The longer my kids wait, the more sight they lose. To us, this surgery is a necessity. On a personal level, it’ll help maintain their quality of life and independence. It’ll allow them to gain and maintain employment. And from a pragmatic societal standpoint, it’ll eliminate their need for further government assistance.

Watching Adam slip into less vision every day because of bureaucracy is heartbreaking. It makes me angry. We need to stop playing disability Olympics and using money as a way of creating further barriers for a community that already lives their life with so many barriers. This is the ultimate barrier.”



**Charmain Brown (Mother of Jenna and Adam)**  
**Pickering, ON**  
**Retinitis pigmentosa**

*The Cost of Vision Loss and Blindness Report calls for research to find innovative treatments to reduce the cost of vision loss, and when they’re approved as treatments, they should be publicly-funded.*



# Knowledge, Awareness, and Early Diagnosis of Diabetes-Related Vision Complications Are Critical

"I started losing my vision 15 years ago, and went through a three-year period of one eye surgery and treatment after the next. I stopped driving, had to leave the job that I loved, and dealt with mental health challenges as a result.

It all started with my diagnosis of type 2 diabetes in 1992 – although I didn't realize the connection at the time. In fact, I wasn't made aware that vision loss was a complication of diabetes until the damage had been done.

In 2005, I developed a cataract in one eye. The cataract surgery didn't go well. When I went to the doctor a couple weeks later for a check-up, he told me that my eye was hemorrhaging (bleeding) and referred me to a retina specialist.

My visit to this specialist was a rude awakening. He told me that all the trouble I was having with my eye had begun with my diabetic retinopathy (DR). I had no idea what he was talking about. 'You've known that you had DR for a couple years, right?' he asked. Not only did I not know, but I'd never even heard the term before. The specialist was stunned, as was I.

My DR – which I'd just learned I had – had progressed to diabetic macular edema. Despite multiple surgeries and 16 rounds of laser surgery, the treatment didn't work. I also had a cataract in my other eye. I started taking anti-VEGFs and they worked for a short time, but I had to go from an eye injection every six weeks to every three and a half weeks eventually, to reduce and manage the bleeding and edema in my eye.

Throughout my journey, I've had many bad experiences with health care practitioners. I was very fortunate to connect with Dr. Geoff Williams about 14 years ago. When my anti-VEGF treatments stopped working, he put me on a steroid treatment that has dramatically improved the bleeding in my eye. Unfortunately, it's not covered by Alberta's drug benefit program – it's only partially funded in Quebec. For years, I was able to take advantage of my partner's private plan, which covered a portion of the medication, but eventually the relationship ended, and so did my access to treatment.

Despite the cost, fortunately, today I'm miraculously stable due to the longevity of this drug, but I make sacrifices to save the vision I have left. I continue to lean on my faith, and on the experience and leadership of Dr. Williams. I've had to surrender much to diabetes and to the vision loss especially, but I remain hopeful that stakeholders will convey the understanding to elected officials for critical funding!"



**Franca Cupello**  
**Calgary, AB**  
**Diabetic retinopathy**

*The Cost of Vision Loss and Blindness Report outlines the importance of early diagnosis of diabetes-related vision complications and of publicly-funded treatment options.*

# Rebuilding a Sense of Self Through Assistive Tech and Meaningful Contribution

“Last year, I completed a second undergraduate degree in Philosophy at the University of Toronto. I’m Chapter President of the CCB’s Visionaries Peer Support Group, which I co-founded, and co-organizer of a Toronto branch of the Get Together with Technology program, a self-directed user group for those interested in assistive technologies.

I was born with congenital glaucoma, and my vision got progressively worse due to surgery complications, ultimately resulting in me going blind.

Going blind was utterly devastating to me. I’d been working as a designer and senior project manager for a design firm, and my sudden vision loss put an end to that. All my personal interests were vision-centered, too – art, architecture, reading, and travel.

I lost my sense of self-identity when I went blind. Every means I had for defining myself was based on what I could do, and what I could do was based on what I could see. I had to reimagine what I could do, how I could contribute, and how I could relate to the people around me, including my daughter, who was four years old at the time.

Assistive devices were extremely valuable in the process of rebuilding my sense of identity. My first piece of assistive tech was a white cane, and the first step in my journey of self-rediscovery was getting good at moving about independently. That led me to exploring other options. I discovered online digital libraries, which opened up the possibility of my continuing to learn, to grow mentally and intellectually, and to be able to keep up with current events.

Assistive technologies that allowed me to read digital content – screen reader software and screen magnification – were critical. To be able to read and write independently again was a game-changer for me. It opened the world to me, and allowed me to connect with what mattered to me.

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



**Ian White**  
**Toronto, ON**  
**Congenital glaucoma**

*The Cost of Vision Loss and Blindness Report identifies accessible technologies as being key to removing barriers for people living with blindness.*

# Clinical Trials in Canada Grant Access to New Sight-Saving Innovations

“I’m visually-handicapped, but I don’t think about this every day. I try to make the most of my life. I’m very happy with my wife, I volunteer for the Groupement des âgés du transport adapté des patriots, and I sing in a choir with people living with vision loss.

It wasn’t always this way, though. When I became officially blind at age 32, it changed my life completely. The life I had planned for myself disappeared. I had studied in trade school as a machinist and mechanic, and worked on repairing airplane engines and machines in my younger years. But to be a mechanic, you need good eyes. So I had to stop working and stay home to take care of my kids, while my wife at the time worked. This changed the way I felt about myself, and had a dramatic impact on my relationship. My wife and I eventually separated.

Ever since my vision began to deteriorate, I’ve had a keen interest in research on genetic eye diseases. By the age of 64, I’d given up hope of ever getting to benefit from any such innovations. But I was lucky, and I was chosen for a Montreal-based clinical trial on choroideremia led by Dr. Robert Koenekoop.

Through this study, I had a sight-restoring operation. After the operation, I noticed with great emotion that I could see things that I couldn’t before. At the hair salon, I noticed the barber’s pole, with its rotating blue, red, and white stripes. I could suddenly see the dark green of the grass, and the twinkling Christmas lights that I install outside every year.

I have four children and six grandchildren, who I’m very proud of. My children didn’t inherit my disease but my two daughters carry the gene, and one of them passed the gene to both of her two sons. This is part of why research is so important to me, and why I agreed to participate in the clinical study. I do it for myself, for my grandsons, and because I believe in it. I’m also convinced that research into these gene therapies for the eyes will prove useful for research on other genetic diseases of all kinds.”



**Pierre Langlois**  
**Saint-Eustache, QC**  
**Choroideremia**

*The Cost of Vision Loss and Blindness Report identifies bringing clinical trials to Canada as being critical to enabling Canadians to have access to new treatments to restore sight at the earliest possible moment.*

# When It Comes to Saving Sight, the Power of Early Diagnosis Is Huge

“Every day, I wake up and think, ‘I’m so lucky.’ Without research delivering innovative treatments, I would be blind.

I’ve had glasses since I was eight, and in my late 50s I was diagnosed with age-related macular degeneration (AMD). My doctor wanted to keep an eye on it and told me what to watch out for. One day as I was driving to a meeting, I noticed that the yellow line on the road was very wavy. I thought to myself, ‘I know exactly what that is.’ And I was right – my AMD had turned into wet AMD. Since then I have also developed glaucoma in my right eye.

With glaucoma, you lose your peripheral vision and with AMD you lose your core vision – so it’s a double whammy, because if you lose both peripheral and core vision, you’re blind.

I’ve had various treatments over the years, and now, managing my eye conditions is quite simple. I’m so lucky because I’m holding my own. My sight is alright, though dry AMD is untreatable.

I was fortunate to be diagnosed and treated early. Early detection is critical, and the other piece of it is taking care of oneself – this is crucial, too. I’m very self-disciplined in taking my twice-a-day eye drops, and I’ve developed other good habits to take care of myself as well. My wife and I are very active. I’ve also been fortunate that my ophthalmologist and team of retina specialists are brilliant.

Because I’ve been able to maintain my sight over the years, I’ve been able to keep working. In fact, I retired in 2012, but the phone kept ringing and contracts kept coming in, so I’m still at it. I have a master’s degree in social work from UBC, and I spent 19 years as the Deputy Director of the Social Planning Department for the City of Vancouver. When I left in the late 1980s, I started a consulting business, and it’s still going strong.

My vision loss has certainly impacted my life. I had to stop playing hockey on the university alumni team, and I use various tools at work, like voice control mechanisms so that I can dictate my emails and reports. But I’m so grateful for the treatments to stabilize my sight and stop it from progressing to full blindness ... 14 years and counting.”



**Doug Purdy**  
**Vancouver, BC**  
**Wet and dry AMD and glaucoma**

*The Cost of Vision Loss and Blindness Report identifies that when it comes to saving sight early diagnosis and innovative treatments are huge.*





# CCB's Research Initiatives Uncover the Cost of Vision Loss and the Impact of the Pandemic on Eye Health

*By Keith Gordon*

## **The cost of vision loss and blindness in Canada**

2021 has been a very productive year for CCB research. At the beginning of the year we released the results of what we regard as the most consequential study on the prevalence and cost of vision loss (VL) and blindness done since 2009. The previous comprehensive study on the cost of VL in Canada was conducted in 2009 using data from 2007. Since 2007, the Canadian population has aged substantially, and a new wave of immigration has led to further ethnic diversification. The primary risk factors associated with the most common eye diseases are age, ethnicity, and genetics. As a result, it can be expected that the prevalence of eye diseases will have changed since 2007, perhaps even significantly. Costs associated with health care delivery and other societal factors have also changed over this period, with new and innovative treatments for eye conditions emerging to alter the vision care landscape. For these

and other reasons, it became crucial that a new and accurate estimate of the cost of VL be developed.

In order to develop an up-to-date estimate of the prevalence and cost of VL in Canada, the Canadian Council of the Blind (CCB) commissioned Deloitte Access Economics (a world-renowned consultancy with expertise in disease prevalence and health economics) to conduct an updated assessment of the prevalence and cost of VL in Canada using contemporary data from 2019. To achieve the stated goals, the CCB partnered with Fighting Blindness Canada, the Canadian Association of Optometrists, and the Canadian Ophthalmological Society.

The study estimated that there are 1.2 million Canadians living with VL, representing 3.2% of the total population. Of this number, 49,500 people were classified as having severe VL or blindness, 417,600 as having moderate VL, and 738,400

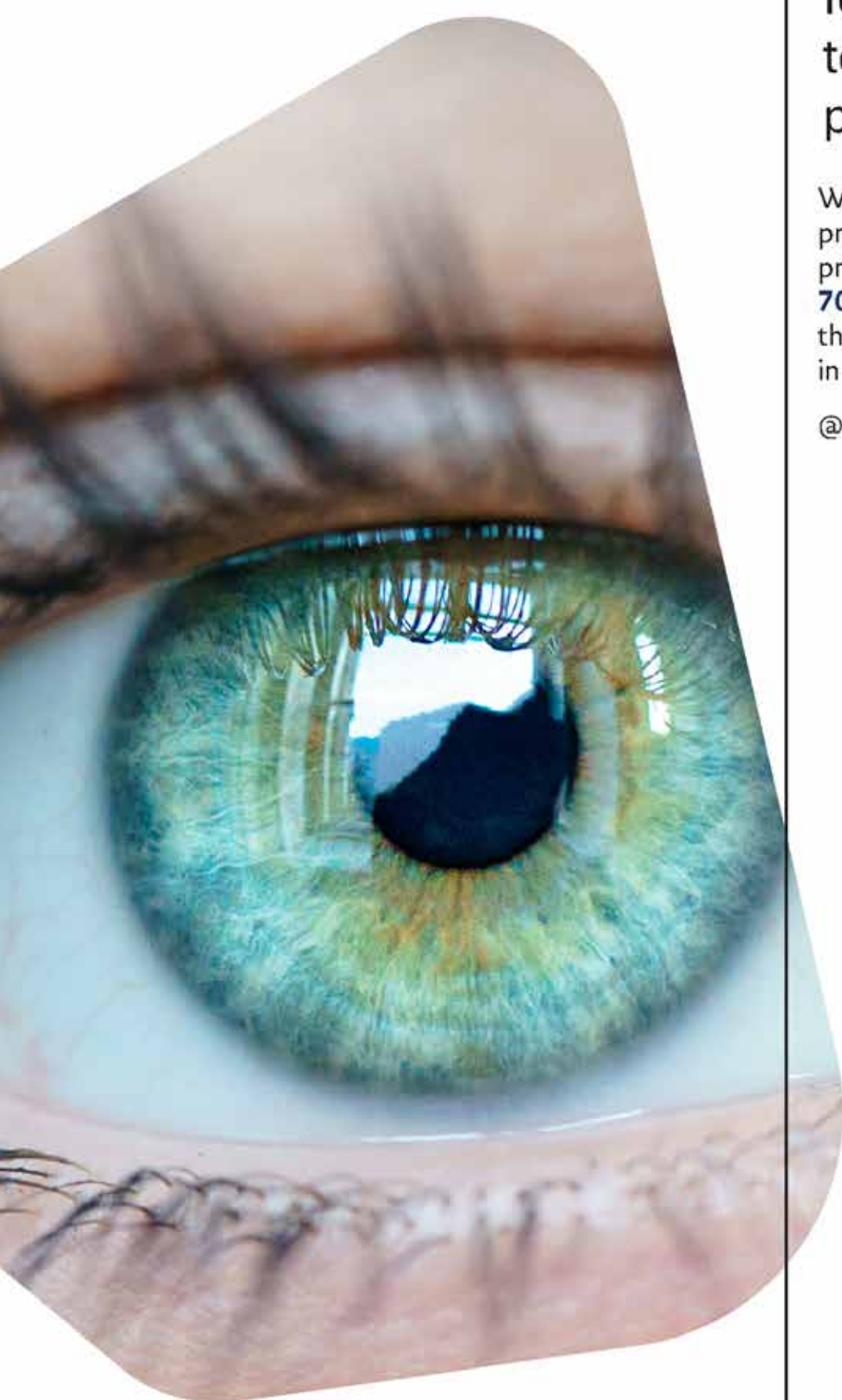
as having mild VL. About one in five Canadians over the age of 85 is living with VL.

In addition to those people currently experiencing VL, the study estimated that there are 8 million Canadians living with an eye disease that may lead to blindness. The study estimated that this number is composed of 2.5 million people living with age-related macular degeneration (AMD); 3.7 million living with cataracts; 1.0 million living with diabetic retinopathy; and 728,000 living with glaucoma. Since many people living with these diseases aren't aware that they have them, it's essential that everyone get regular complete eye examinations from an eye doctor so that these diseases can get diagnosed and treated as early as possible. Early diagnosis and treatment can decrease the likelihood of serious VL.

The study went on to estimate the total cost of VL in Canada in 2019

*Continued on page 38*

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at \$32.9 billion. This consists of a total financial cost of \$15.6 billion, and a lost well-being cost of \$17.3 billion. The major contributors to the financial cost of VL were health system costs of \$9.5 billion incurred by people with VL and productivity losses of \$4.3 billion due to unemployment and underemployment of people with VL.

Based on trends in population growth and aging, the cost of VL in Canada was estimated to grow from \$32.9 billion in 2019 to \$56 billion (in 2019 dollars) in 2050.

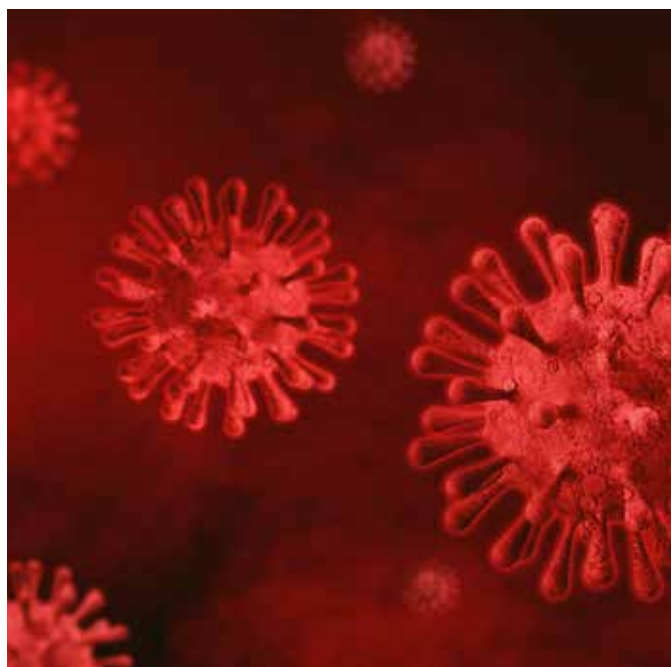
Noting that it's estimated that 75% of VL can be prevented or treated if diagnosed early enough, the study report made several recommendations for mitigating the growth in the prevalence and cost of VL. Foremost among these was the recommendation that the Canadian government develop a national vision health plan for Canada that could be used as a template for the provinces to develop provincial vision health plans. The report also urges the Canadian government to establish a Vision Desk in the Public Health Agency of Canada in order to more effectively plan for the prevention and treatment of VL in Canada.

## **The impact of the COVID-19 pandemic on eye health in Canada**

The second study commissioned by CCB research in 2021 was an addendum to the cost of VL and blindness in Canada study discussed above.

The COVID-19 pandemic has had an enormous impact on health care systems and practices around the globe. This extends to crucial and often sight-saving ophthalmic surgeries and services in Canada, which saw a dramatic reduction in 2020. For this reason, it was deemed essential that the cost of VL and blindness report be updated with an addendum that assesses the impact of the pandemic on the reported prevalence and cost of VL. To adequately plan vision health services for the future, it's necessary to understand the impact that the pandemic has had on the provision of services and what will be needed in the future to overcome any additional problems and backlogs created by the pandemic.

The addendum report, released in October 2021, estimated that 1,437 Canadians experienced VL due to delayed eye examinations and treatments in 2020. Almost all optometrists' offices were closed during the first lockdown from March to June 2020, with most offices restricting capacity for the rest of 2020. The study estimated that there were 2.9 million fewer visits made to optometrists in 2020 compared to 2019. The resulting reduction in early diagnosis and treatment of eye diseases



put millions of people at risk of experiencing VL. The study further reported that 143,000 eye surgeries were missed or delayed in 2020, and that almost 70,000 fewer eye injections for the treatment of AMD and diabetic retinopathy were performed in 2020, further contributing to the number of people experiencing VL.

The impact of the pandemic will be felt well into 2023. Wait times for cataract surgery were estimated to have increased by 31 days in 2020 and it's expected to take two years to clear the surgical backlog at an additional cost of \$129 million per year. The health system is expected to incur an additional cost of \$1.4 billion between 2021 and 2023.

COVID-19 continues to challenge the Canadian health care system. The full extent of the impact of cancelled and delayed ophthalmic care is still unclear. Further challenges lie ahead for the Canadian health care system as it continues to address subsequent waves of the pandemic and ongoing disruptions to ophthalmic services. The impact of the pandemic on vision health further reinforces the need for a national vision health plan for Canada.



*Keith D. Gordon Ph.D.  
is CCB Senior Research Officer*



# 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.



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DIABETES  
CANADA

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Canadian Ophthalmological Society  
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# Canada's Failure to Deliver on Universal Eye Health is Costing the Country Billions of Dollars

BY DIANE VAN STADEN

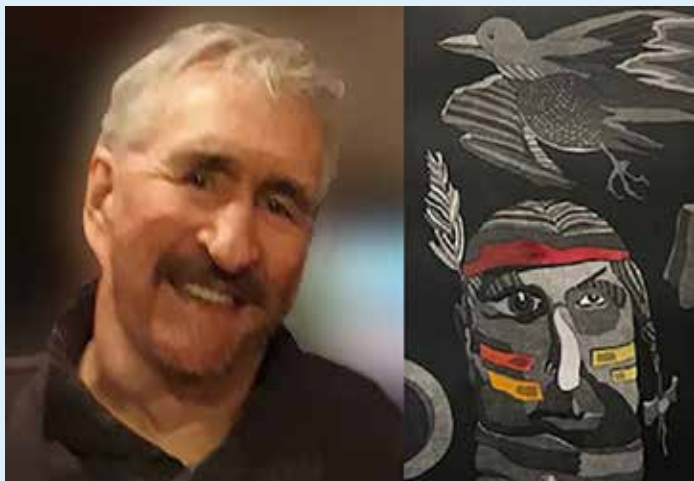
While Canada has continuously supported the World Health Organization (WHO)'s resolutions on eye health, evidence is that commitments Canada made as far back as 2003 have still not been met. Universal eye health is a component of universal health care, a principle on which the Canadian healthcare system is based. In 2003, Canada supported the WHO's 'Vision 2020: The Right to Sight' initiative as part of the Global Initiative for the Elimination of Sight Avoidable Blindness. In 2013, Canada again supported a resolution at the 66th World Health Assembly, 'Towards Universal Eye Health: a Global Action Plan 2014-2019'. The principle commitments member states agreed to in the latter included (i) to strengthen national efforts to prevent avoidable visual impairment through better integration of eye health into national health plans and health service delivery, and (2) to implement the proposed actions in the global action plan 2014-2019 in accordance with national priorities, including universal and equitable access to service. The main goal of GAP was to reduce avoidable visual impairment as a public health problem and to secure access to rehabilitation services for the visually impaired. However, for the majority of Canadians, access to eye care services remains a challenge.

Uncorrected refractive error is a major cause of vision impairment globally; yet Canada does not provide universal coverage for routine vision care services to all its citizens. Provision of effective and accessible eye care services

is key for controlling vision impairment and blindness, and promotes the integration of comprehensive eye care services as part of health systems development. Vision loss is estimated to cost Canada almost 33 billion dollars annually. The unfortunate reality is that Canada still has not made the relevant policy shifts in terms of addressing the structural barriers to all of its citizens accessing primary eye care services within its health system; which is key to early intervention and diagnosis of eye diseases, as well as reducing long term care costs. Canada is accountable to the WHO for implementing approaches which support universal eye health, in keeping with its commitments; yet Canada's 2003 commitment to developing a national plan for eye health has still not been met. With the further impact of population growth and ageing, Canada simply cannot ignore the reality of its unmet eye care needs and must address barriers to access for its citizens, including appropriate financing of eye care services, if it is to meet the WHO's imperative to provide universal eye health coverage and reduce avoidable vision impairment.



*Dr Diane van Staden is a South African optometrist and academic at the University of KwaZulu-Natal. She is currently a Visiting Assistant Professor at the University of British Columbia.*



## Remembering Richart Bocxe (1949 – 2021)

BY MICHAEL BAILLARGEON

The Canadian Council of the Blind (CCB) has lost a key team member with the passing of Richart Bocxe this last December. Richart passed away from complications after a lengthy and courageous battle with cancer. Rich had just turned 72 and was, for the last 17 years, the Council's chief graphic designer. He was the third child in his family and leaves nine siblings in Holland and one in Ireland.

In 1982 he left the advertising business in Holland and immigrated to Calgary where he pursued his life-long passion of painting, while employing his professional graphic arts experience.

Rich was a skilled graphic designer whose talent and understanding of the product we required for White Cane Week made our lives easier and his finished product made us all look good. Richart created the graphic face of the CCB's public persona, not only with his creativity, represented in White Cane Magazine, but with our event programs, advertising, promotional material, logos, research studies, and more.

He was a true friend of the CCB always willing to go the extra mile to create a better product. Richart was an absolute pleasure to work with, kind, considerate, and generous. He will be greatly missed by all who had the good fortune to know him.

Rest in peace, dear friend.

## 'It's Just So Empowering': Calgary Club Teaches Visually Impaired Kids How to Skateboard

BY HANNAH KOST, CBC NEWS

A young girl in a blue helmet tentatively approaches a sloped bowl in the smooth, grey pavement at a skate park in the west end of downtown Calgary that has been marked with brightly coloured tape. Seconds later, she travels down on her skateboard in a confident swoop, and applause meets her at the bottom.

Grace Forsyth, 13, is a member of Skate Bats, a club established in 2019 that teaches visually impaired and low-vision kids how to skateboard.. "I'm moving without moving my legs, but I still have control of where I go," Grace said. Seeing Grace cruise through the park with the other Skate Bats is thrilling too, for her mother, Christine Forsyth. "It's amazing to me to watch them," Christine said. "Their confidence just grows every week."



"The members of Skate Bats live with different types and degrees of vision loss, but most are low-vision enough to be registered with the Canadian National Institute for the Blind", said founder Matt Janz – but he said the Skate Bats have a lot more in common than that. "They have the courage and the work ethic. And what we've seen is, they've been learning how to skateboard better than most people could, to be totally honest."

### 'IT GIVES ME HOPE ABOUT LOSING MY OWN VISION'

Janz has a hereditary condition called retinitis pigmentosa, and he says it means he has been slowly but surely losing vision throughout his life. He has loved to skateboard nearly as long. "When I was a little kid,



probably six years old ... I think my mom bought me, like, a banana board from a garage sale," Janz said. "The first ride down the driveway was it."

Skateboarding helped him find an identity and a community, he said. Passing that on to others helps him feel inspired. "It gives me hope about me losing my own vision," Janz said. "The more I skateboard as a visually impaired person, the more I feel like I have a future, and something to do – despite how much vision that I may or may not use."

Just about every Saturday, the group meets at Shaw Millennium Park around 10 a.m. to skate in what is normally a sea of grey – Janz says they call it "the ghost bowl."

"We can't see when the ramps begin and when the end, so any change of angle of the riding surface is totally invisible to us," he said. But the club uses high-contrast tape to help Skate Bats like Zachary Abdalla, 14, identify transitions in the pavement – where ramps start,

when they end, and how skate boarders should adjust their weight.

"It's fun, exhilarating, all that shenanigans," Abdalla said. "But just like related to vision loss, it's scary – probably more scary than for most people. The Skate Bats staff and volunteers coach and cheer them through.

## THE WHOLE WORLD IN FRONT OF THEM

For now, the Skate Bats club is small – six to eight kids, Janz said. But Janz has plans for the future, and describes himself as a pretty big daydreamer. These kids have the whole world in front of them. "It's just so empowering, the way that they're being given the opportunity by their parents to come out and do stuff like this." "Just because they were given the chance to skate," Janz said

"And they were given the chance to develop their skills and become a skateboarder."

*With files from Dan McGarvey, CBC News.*





## Every Step Counts: Blind Chicks with Sticks Take a Virtual Cross-Canada Walk

**BY SHELLEY ANN MORRIS, CCB**

Last year, seven women who have vision loss took a virtual walk from Vancouver, BC, to Signal Hill, in Newfoundland. Along the way, they learned more about Canada, motivated each other, and maintained good physical health and social connections in the face of a pandemic.

Lois Friesen is a regular participant in Get Together with Technology (GTT)'s weekly chat sessions on Zoom. Lois' friend, Larena Blanchard, wanted to form a walking group with friends who live in and around Edmonton, Alberta. When travel restrictions and stay-at-home orders were imposed due to COVID-19, they decided to embark on a virtual walk instead. Larena had done a virtual walk with colleagues and had also travelled across Canada with her husband. Everyone was eager to participate, and Blind Chicks with Sticks was launched in April 2020.

### MAKING A CROSS-COUNTRY TREK, VIRTUALLY

Five of the seven members use white canes. These canes have become valuable tools at this time as they help to keep others at a safe distance – particularly for people with little or no peripheral or 'side' vision. Additionally, a white cane helps to identify those with vision loss, and to let others know that they have a good reason for not being able to follow the directional arrows on the floor, or for going in through the out door.

The women in this group walked individually, tracking their steps using health apps, Apple watches, and Fitbits, as these are all accessible with screen-reading and magnification software.

Each week, the group would submit the number of steps they'd walked. Weekly updates using Google Earth were posted on the group's Facebook page, including interesting stories about the histories of the places they virtually visited and descriptions of landmarks they'd discovered along the way.



## EVERY STEP COUNTS

This was truly an exercise for both body and mind. Each week, the chicks would check in for motivation and encouragement, and to exchange tips and strategies for getting their steps done. As everyone's situation is different, there was no competition – every step counted, with an emphasis on mutual support. Talk would turn to all aspects of walking, including the best kind of winter boots to wear.

Lois said that she likes to walk along Telford Lake with her husband. Larena described walking in Southern Alberta in the mountains with her family. Walking around during commercial breaks while watching TV, in the kitchen while heating up a coffee in the microwave, and while doing laundry or going to the grocery store were all seen as creative ways to accumulate more steps. The Blind Chicks with Sticks also took walks in their own neighbourhoods, in malls and on home treadmills.



Vision loss need not keep anyone from enjoying a walk. "Just because you're blind or have low vision, doesn't mean that you can't be fit and healthy and do things independently or with a sighted guide," said Larena.

## THE JOY OF ADVENTURE

On December 6, 2020 with 7,228 kilometres walked and 11,852,473 steps taken collectively, the Blind Chicks with Sticks reached their goal, and were 'screeched in' on Zoom, supplying their own beverage of choice, and substituting tuna for cod. On January 29, 2021 they set out on their next adventure – a virtual walk around Alberta.

The Blind Chicks with Sticks have demonstrated by example that neither COVID-19 nor loss of sight can stop them. With increased numbers of people receiving

vaccinations, and the anticipated gradual loosening of restrictions, this is a great way to be active and stay connected with others.

## UN Votes to Provide Access to Eye Care for Everyone



BY EDITH M. LEDERER, "ASSOCIATED PRESS"

New York - New York - The UN General Assembly approved its first-ever resolution on vision, calling on its 193 member nations to ensure access to eye care for everyone in their countries, which would contribute to a global effort to help at least 1.1 billion people with vision impairment who currently lack eye services by 2030.

The "Vision for Everyone" resolution, sponsored by Bangladesh, Antigua and Ireland, and co-sponsored by over 100 countries, was adopted this month by consensus by the world body. It encourages countries to institute a "whole of government approach to eye care." And it calls on international financial institutions and donors to provide targeted financing, especially for developing countries, to address the increasing impact of vision loss on economic and social development.

According to the resolution, "at least two billion people are living with vision impairment or blindness and 1.1 billion people have vision impairment that could have been prevented or is yet to be addressed." "Global eye-care needs are projected to increase substantially, with half the global population expected to be living with a vision impairment by 2050," the resolution says.

Bangladesh's UN Ambassador Rabab Fatima introduced the resolution, stressing its first-ever focus on vision, and

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calling it “a long overdue recognition of the central role that healthy vision plays in human life and for sustainable development.” She said more than 90 per cent of the 1.1 billion people worldwide with vision loss live in low- and middle-income countries, adding that 55 per cent of blind people are women and girls.

The loss of sight costs the global economy “a staggering amount of \$411 billion (USD) in productivity each year,” Fatima said. Access to eye-care services can increase household spending per capita by 88 per cent “and the odds of obtaining paid employment by 10 per cent.”

While General Assembly resolutions are not legally binding, they do reflect global opinion. Fatima said it was critical for the assembly to convey the UN’s “unequivocal commitment to ensure proper eye care facilities for everyone, everywhere, to prevent conditions which can lead to serious and permanent damages. “She called the resolution an “opportunity to change the lives of millions who are living in blindness or with impaired vision.”

The resolution stresses that access to eye care is essential to achieve U.N. goals for 2030 to end poverty and hunger, ensure healthy lives and quality education, and reduce inequality. It calls on all nations to mobilize resources and support to ensure eye care for all people in their countries, in order to reach at least 1.1 billion people worldwide “who have a vision impairment and currently do not have access to the eye care services that they need” by 2030.



### **The Canadian Council of the Blind Stands with Ukraine**

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

The Russian and Belarusian Military assault on Ukrainian settlements has taken the lives of innocent civilians. This unjustified war violates all norms of international humanitarian law.

The CCB joins the Ukrainian Association of the Blind in urging the European Union of the Blind and the World Blind Union to condemn the violence in Ukraine and to call on the Presidents of Russia and Belarus to cease hostilities.

We further urge the European Union of the Blind and its members in Europe to provide all possible assistance and accommodation to refugees from Ukraine with visual disabilities. We strongly encourage Russia and Belarus to respect their international obligations and ensure protection and safety for all persons with disabilities in accessing safe evacuation and humanitarian assistance.

# Thank You – We Couldn't Do It Without You

As we celebrate White Cane Week 2022, 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.

Your continued presence is necessary if the CCB and this celebration of White Cane Week are to continue to grow and develop. Therefore, it is

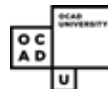
important, that you as a group at the corporate level, as fellow stakeholders and partners, and as individuals, understand our gratitude and appreciation for your confidence in, and support of, the Council not only this week but year round.

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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A photograph of a smiling grandfather with grey hair and a beard, wearing a light pink shirt, carrying a young child on his shoulders. The child is also smiling and wearing a pink shirt. They are outdoors in a park-like setting with green trees in the background.

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