# WHITE CANE

**MAGAZINE** 

**Summer 2024** 



The Commemorative 80th Anniversary Edition

# For the love of sight

Proudly working with you toward our shared goal – a future where vision lasts a lifetime.

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# **PUTTING A LENS** ON BIOSIMILARS

Your vision matters and it's important to clearly understand emerging vision care options and why they are trusted, high-quality medicines.

### THE TOP 3 THINGS YOU SHOULD KNOW

Biosimilars are a type of biological medicine (or "biologic"); biologics are complex in structure and are manufactured using living cells.1



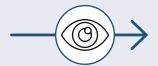
A biosimilar is highly similar in structure to an existing original biologic medicine (called a reference product).1

A Health Canada-approved biosimilar has no clinically significant differences in safety and efficacy compared to the original biologic.1



A biosimilar is subject to rigorous clinical testing and evaluation prior to being approved - it can take five to 10 years to develop a new biosimilar - and works the same way as the reference biologic drug.2

Biosimilars are emerging as effective options for the treatment of vision disorders.3



Patients who are prescribed a biosimilar medication instead of the original biologic are receiving the same standard of treatment.1

### **QUICK FACTS**

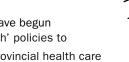
Health Canada has approved ~50 biosimilars since 2009

to treat serious conditions like cancer, diabetes, rheumatoid arthritis, and now, retinal disease.3



Patients have been safely switching from original biologic medicines to biosimilars throughout North America and Europe since 2006, without compromising efficacy or quality of care.4

Biosimilars can be offered at a lower cost than the original biologic, which can **bring value** to health systems and support patient access to advanced therapies.5



Some provincial formularies have begun implementing biosimilar 'switch' policies to reinvest savings in provincial health care services.6

Vision loss and impairment impacts independence, employment opportunities, and can cause anxiety, fear and social isolation. Biosimilars have the potential to help more Canadians access treatment that can help preserve vision health and quality of life.











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As a long-time partner of the Canadian Council of the Blind, AMI extends sincere congratulations on 80 years of improving the lives of Canadians who are blind or partially sighted. It has been our pleasure to share CCB stories through our various programs available on AMI-tv, AMI-audio and on AMI+.

Congratulations, from your friends at AMI.



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# President's Message



PHOTO: ANDRE MARTIN

As the Canadian Council of the Blind (CCB) marks its remarkable 80th anniversary this year, it gives me great pleasure to reflect on the journey that has brought us to this significant milestone. From our modest beginnings to our current stature as a beacon of empowerment and progress, the CCB has continuously evolved to meet the needs of our community.

In this issue, we're excited to present an article tracing the rich history of our organization, highlighting our journey of growth and progress. From our foundational focus on recreation and advocacy, we've expanded our horizons to pioneer transformative programs, engage in ground-breaking research, and forge powerful collaborations for stronger advocacy. Join us as we celebrate our legacy and look ahead to the exciting future as we continue to enhance the lives of Canadians who are blind, Deafblind, and partially-sighted.

During the upcoming Annual Gathering Dinner on the evening of May 21, the Council will bestow its annual awards on two extremely worthy recipients. The 2024 Person of the Year is long-time member and Director Heather Hannett (see page 11) while the President's Award will recognize Dorothy Macnaughton's long-term commitment to the CCB Sault Ste. Marie White Cane Chapter and the people of Northern Ontario (see page 13). Both Hannett and Macnaughton continue to serve their communities with dedication and respect. They're truly making a difference and are changing what it means to be blind.

February witnessed another successful CCB conference. The first part of the conference was a collaboration between the CCB and Fighting Blindness Canada to mark Age-Related Macular Degeneration (AMD) Awareness Month. The keynote speaker, retina specialist Dr. Bernard Hurley, gave us an overview of AMD and its treatment, and then, in a very lively question-and-answer session, addressed a number of questions that the large audience had with respect to this disease. Three people with lived experience of AMD also presented the issues that they've faced due to the condition. The second part of the conference consisted of presentations from researchers from Statistics Canada, who discussed their overall mandate with respect to providing usable statistics related to disability. These researchers also discussed the findings of the 2022 Canadian Survey on Disability.

An integral part of the history of the CCB is the initiatives we've undertaken over the past six years

in the areas of research and advocacy. The data generated from our research has been used to support a robust advocacy campaign on a number of fronts, by both the CCB and other organizations. The CCB has advocated strongly and successfully for the Canadian federal government to develop a national vision health plan. Bill C-284, "An act to establish a national strategy for eye care," was introduced into the House of Commons in June 2022. The bill has been approved by the House of Commons and is awaiting ratification by the Senate. Bill C-284 will positively change the lives of not only those living the experience of vision loss but all Canadians. I extend kudos and gratitude for the tireless efforts of the Honourable Judy Sgro, MP (Humber River-Black Creek).

Recommendations from the Ontario Assistive Devices Program (ADP) survey have been used as the basis for the Terms of Reference of an ADP working group designed to reform the ADP. The CCB has led this initiative along with an amazing working group comprised of key vision health stakeholders, all of whom are enthused that exciting, tangible results are imminent. In short, we've established a sound basis for research and advocacy that's making a difference not only in the lives of people who are blind or partially-sighted but in the lives of all Canadians, by advocating for initiatives dedicated to preventing blindness.

Enjoy this special issue of *White Cane Magazine* as we look back over the 80-year history of the CCB as well as major advances in innovative medicine and the appearance of new assistive devices and technology. Join us in Celebrating May's Vision Health Month!

**Jim Tokos** 

**National President** 

Canadian Council of the Blind





Genetic testing may empower you and your family by giving you valuable answers.



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Sometimes there is no known family history of inherited retinal disease, but it is still genetic.



Follow the QR code to the testing discussion guide. **EYESONGENES.CA** 

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#### **EDITORIAL**



PHOTO: ANDRE MARTIN

# Technology Can Make Lives Easier, but Only If It's Accessible for All

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

In Canada, more than 800,000 people are blind or vision-impaired. Since the most common eye diseases are age-related and Canada's aging population continues to increase, the number of Canadians with blindness or partial sight is expected to double in the next 25 years.

Canadians living with vision loss now rely heavily on technology to assist with their daily living requirements. And when it works, this tech is fantastic! Many of us are now walking around with a tiny computer in our pocket, otherwise known as a smartphone. These handy little devices have out-of-the-box accessibility features built in, such as magnification and voice over. This means we don't need to shell out big bucks to make phones work for us – they come already complete with handy features that anyone can turn on or off. And with these smartphones, we can use any number of apps for reading, communicating with friends and family, travelling, and wayfinding.

However, when tech items aren't accessible, they're rendered useless to the growing population of individuals living with blindness. For example, more and more devices are moving away from tactile buttons and replacing them with touchscreens. If I'm looking for a new stove, I need to make sure it has tactile knobs so that I can actually use it and cook dinner for my family. However, since many stoves have touchscreens, my options become limited. Maybe I can only afford a lower-priced item but am forced to purchase the more expensive version because that's the only one I can use.

As the world moves more online, we need to ensure that we advocate for technology to be accessible and user-friendly for all. The Canadian Council of the Blind (CCB) continues to work hard on behalf of the community of people with vision loss to put pressure on government and industry to make sure devices are able to be used by all Canadians.

We also know that one of the major voids within the community of people living with vision loss is acquiring and training in assistive technology. Knowledge in this area can transform an environment of isolation and desperation into a productive, meaningful, and fulfilled life.

The CCB is addressing this issue with our Get Together with Technology (GTT) program, which provides computer literacy training as well as a space for individuals to support each other. The program is designed to enable individuals living with blindness to gain access to information and communication through computers and adaptive technology.

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

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

**Mike Potvin** 

**Editor** 

2024 White Cane Magazine

# Empowering Patients to Navigate Their Eye Health with Confidence

The Power of the Community in Developing Valuable Resources



It's important to visit an eye care professional regularly to help protect your eye health PHOTO CREDIT: ISTOCK.COM

ision loss can be devastating to Canadians, regardless of their age. In fact, more than 1.2 million Canadians live with vision loss today,¹ and one in seven Canadians will develop a serious eye disease in their lifetime.² Blinding diseases affect older adults (55+) at much higher rates,³ and as Canada's population ages, the number of individuals affected by vision impairment will continue to rise.

As we recognize Vision Health Month this May, it's a valuable time to remember the importance of being proactive about your vision, being aware of any changes to your eyesight, and ensuring you get annual eye exams.

For those who receive a diagnosis of an eye disease, it can bring up different questions and feelings, and people may not know where to turn for support or accurate information.

In order to address a gap in available resources for people living with eye conditions like age-related macular degeneration (AMD) or diabetic retinopathy (DR), Roche Canada partnered with health care professionals, patient groups, people living with eye diseases, and their caregivers to co-create educational resources to help provide them with the knowledge they need to navigate their diagnosis with confidence.

One key partner in co-creating the materials has seen first-hand what people experience upon receiving a diagnosis with an eye condition: "People often experience feelings of fear and panic," says Jim Tokos, National President, Canadian Council of the Blind. "It's important that they have materials

to identify and address their needs when navigating their diagnosis in a simple and manageable way."

Fighting Blindness Canada, another contributor to the creation of resources for the community, understands that patients may not always know how to approach their upcoming appointments with their eye care specialist, and can often feel overwhelmed: "Having resources to help a patient navigate conversations with their eye doctor is important because it can help them understand more about their condition, and to know what questions to ask," says Morgan Ineson, Senior Manager, Education, Fighting Blindness Canada. "Access to clear and plain language information helps patients to advocate for the best care for their eye health."

Having the right information at your fingertips to help you navigate your journey with ease is critical.

"With the right tools and resources to support, there can be life after vision loss," says Tokos. "We want to help provide the community with resources that can help not only advocate for themselves, but to help them continue to live active lives and do the things they enjoy."

If you've been recently diagnosed with an eye disease like diabetic retinopathy or AMD, or are looking for resources and support, you can visit <a href="https://www.eyehealthmatters.ca">www.eyehealthmatters.ca</a> to learn more.

This article is sponsored by Hoffmann-La Roche Limited (Roche Canada).

<sup>1</sup> https://www.fightingblindness.ca/wp-content/uploads/2021/05/KG-EN-ACC-Cost-of-Vision-loss-and-Blindness-in-Canada-Final.pdf 2 https://opto.ca/vision-health-month#:-:text=Did%20you%20know%20that%201,high%20blood%20pressure%20and%20diabetes

https://www.cos-sco.ca/vision-health-month-canadas-aging-population-highlights-need-to-prioritize-eye-health-and-vision-loss-prevention/

# Heather Hannett Named the 2024 Person of the Year

This year's Person of the Year is Heather Hannett, a long-time supporter of the CCB and Chair of its Membership Committee, whose caring leadership fosters membership growth and guides fellow board members.



ongratulations to Heather Hannett,
National Board Member for the CCB
Alberta Division and member of the CCB
Calgary Club, who is this year's recipient of the
Person of the Year Award.

Hannett has been a proud member and supporter of the CCB since the early 2000s and currently serves as Chair of the Membership Committee, where she utilizes her extensive experience and interpersonal skills to foster community engagement and cultivate relationships with prospective members. Through strategic outreach initiatives and personalized communication, she effectively conveys the value of CCB membership, ultimately driving growth and retention. Known for her unwavering dedication and compassionate nature, Hannett also leverages her leadership role to mentor fellow board members and CCB peers, offering guidance and best practices to optimize their contributions and contribute to enhanced membership growth from coast to coast.

Hannett is also being recognized for her outstanding contribution in her efforts with Alberta Gaming and its impactful contribution to the members it serves in Alberta. The fundraising through the gaming initiative allows the CCB Calgary Club to secure office space, which is a valuable commodity. This space gives the membership a place to congregate and provide peer support to each other through group activities such as cribbage. Other activities the club supports include bowling, curling, yoga, hockey, and lawn bowling, with bowling being the most popular activity of all.

"These activities bring out a lot of new people and introduce them to the CCB, as well as showcase people's abilities," says Hannett. "These individuals end up getting involved and getting active, and that's what's really important to me and what I feel is the true mandate of the Council."

Hannett is very involved with the CCB Calgary Club, which boasts over 55 members. One of her favourite activities with the club is the weekly cribbage that the Calgary members participate in, drawing over 20 members each week.

"We noticed that through activities such as cribbage, members started to learn braille," says Hannett. "So, we took the opportunity to start a new group to teach braille."

Another initiative the Calgary Club started recently was producing certificates to provide to the bowling lanes, curling rink, and other supportive locations, which helps to promote the club to new people.

"The best part for me is when we get a new member," says Hannett. "I've seen individuals who started out very hesitant and quiet. As they attend more activities through the Council, I watch them come out of their shell and get super involved. I love seeing that!"

Looking to the future, Hannett would like to continue expanding the CCB throughout the province, especially in rural communities. "I've noticed more folks are coming out now that COVID is over," she says. "I'd like to continue that trend."

Hannett's mantra is that when members at all levels of the organization communicate and work together as a united front, we can do great things.

"Heather exemplifies a true dedication to the values of the Council with her outstanding dedication and work ethic," says Jim Tokos, National President of the CCB.

We're sure that under Hannett's direction, the Council will continue to grow in the province, and more people will take advantage of the wonderful activities and peer support the groups provide. Congratulations Hannett and thank you for all your support and dedication over the years!



# FIGHTING BLINDNESS CANADA CELEBRATES 50 YEARS OF PUTTING SIGHT-SAVING RESEARCH IN THE SPOTLIGHT

Through groundbreaking research, innovation, and advocacy, we have invested more than \$45M in research and educational programs that have improved the sight and lives of countless people, and fuelled progress towards a future free from blindness. Learn more at: fightingblindness.ca



# LET'S MOVE FOR SIGHT TOGETHER ON SUNDAY, JUNE 23, 2024!

Join Canadians nationwide as we all **MOVE** for critical sight-saving research in our new fundraising challenge. Whether you walk, run, cycle, dance, or even cook, your movement supports crucial research and education. Join a team or go solo — every **MOVE** counts. Let's **MOVE** for sight together! Get moving at: **moveforsight.ca** 



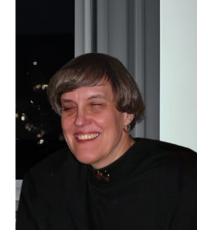
# HELP SHAPE THE FUTURE OF FIGHTING BLINDNESS CANADA!

Share your insights in our short survey. Help guide our vision loss research and education efforts. Your input matters! Survey closes May 24. Confidentiality assured. If you require assistance, email: bbalfour@overlapassociates.com. Participate in the survey at:

fightingblindness.ca/survey

# Dorothy Macnaughton Awarded the 2024 President's Award

This year's President's Award recipient is Dorothy Macnaughton, a dedicated Canadian Council of the Blind (CCB) chapter leader whose unwavering commitment has significantly impacted the lives of visually-impaired individuals in Northern Ontario.



ongratulations to Dorothy Macnaughton, from the CCB Sault Ste. Marie White Cane Chapter, who is this year's recipient of the President's Award. Macnaughton is receiving the award as a result of her long-term service in the Northern Ontario region, including her work with the Get Together with Technology (GTT) program. "My number one priority is the CCB chapter here in the Sault," she says. "It's all about improving services for our members and the disabled community as a whole."

The chapter will celebrate its 25<sup>th</sup> anniversary this June, and what has sometimes been a small group of only 8 to 10 members is now up to 25 and growing.

"I believe the success of the group is based on the people who started it along with those who continue to contribute, especially the volunteers," says Macnaughton. "For example, last year we hosted an AccessAbility Week Information Fair, and it was a huge success in terms of promoting the chapter to new members."

As the only physical vision loss support group in Sault Ste. Marie, the chapter also invites people from outlying areas to join. It offers a warm, welcoming environment where everyone is invited to share their experiences living with vision loss and to support each other.

Macnaughton is also extremely dedicated to the Northern Ontario and Rural contingent of the GTT program, which gives individuals a chance to meet up and share tips on assistive technology. This enthusiastic group of tech-interested people has been meeting for over 10 years. Its members love to share ideas and information regarding technology, which is so integral to the blind and visually-impaired community these days. These popular meetings are held over Zoom, where it's not uncommon

for members from all across Canada to join in, including some real tech experts. Typically, the group will choose a topic to cover, and then this is followed by a general question-and-answer period.

Another thing that Macnaughton is clearly passionate about is advocacy. Recently, transportation services in Northern Ontario have diminished, and she's a staunch advocate for maintaining these services and expanding them where possible. Macnaughton is the Chair of Ontario Northland's Accessibility Advisory Committee (AAC), which advocates for accessible transit, including regional buses and the Polar Bear Express Passenger Train. She has also been working to reinstate the Northlander, which is a train from Toronto to Timmins. "Two members of the AAC spoke up and said that we needed buses that included somewhere to put guide dogs," says Macnaughton, while reflecting on an improvement to accessibility. "And now they've just purchased two new buses with more leg room, where dogs can rest comfortably, instead of having to put them in the aisle."

When it comes to this year's President's Award, the ever-humble Macnaughton is honoured to receive it, but feels she is truly receiving it on behalf of her CCB chapter. "It's nice to be recognized, but I do this work for the people in my community," she says. "It's really about them."

Macnaughton says it can all be summed up by what one of the members of the group told her during one of their meetings: "This chapter is making such a difference in my life, and I don't know what I'd do without it."

We know that Macnaughton is making a huge difference in people's lives with her work in the CCB and we thank her so much for her hard work and dedication to the members.

# Major Innovations in the Treatment of Eye Diseases since 1944

Here's a look back at more than 50 years of advancements in eye care and ophthalmology – and a glimpse of what's on the horizon.

#### **DR. KEITH GORDON**

#### 1947

This year marked the implantation of the first intraocular lens, a lens that's implanted into the eye to replace the natural lens which has become opaque due to cataract formation.



Dewey S. Understanding Intraocular Lenses: The Basics of Design and Material. *Focal Points*. 2015.

#### 1960

The first glaucoma implant is developed, which allowed fluid to drain from the eye through a tube, thus lowering eye pressure. People with difficult-to-treat glaucoma now have an option to slow or even prevent vision loss as a result of their condition. Modifications of these devices continue to be used.

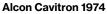
#### 1961

The first use of fluorescein dye to visualize blood vessels in the retina is reported. This fluorescent dye allows the retinal blood vessels to be visualized and damage from diseases such as diabetes to be recognized and treated.

#### 1967

Cataract surgery is revolutionized by the introduction of a procedure called phacoemulsification ("phaco") to remove cataracts. This procedure uses an ultrasonically vibrating needle to break up and remove cataract-damaged lens material from the eye through a tiny opening, allowing much more rapid visual recovery after surgery.







**Alcon Centurion 2024** 

#### 1972

Vitrectomy surgery is first successfully demonstrated. This procedure uses a miniature cutter which is housed in a needle to safely remove the vitreous from the back cavity of the eye. Vitreous is like a raw egg white and is involved in retinal detachments, diabetic retinopathy, macular holes, and several other serious eye diseases.

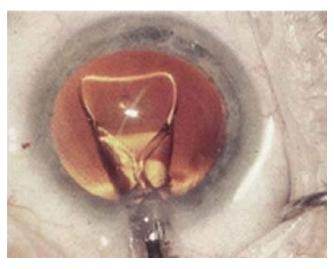
#### 1978

Timolol, a beta-blocker (a drug used to treat heart conditions), is approved for the treatment of glaucoma in eye drop format. Timolol continues to stand the test of time and is still widely used today.

# 1978-1991

#### 1978

The foldable intraocular lens is developed. This allows the lens implant to be placed into the eye through small incisions. This minimizes post-operative recovery time and improves vision after surgery.



Davison JA, Kleinmann G, Greenwald Y, Apple D. Intraocular Lenses. Available at: entokey.com/intraocular-lenses-2/

#### 1979

First reported use of lasers to treat glaucoma. This early approach was found to be effective for several years but eventually failed to control pressure in the eye. It has been replaced by newer laser techniques.

#### 1982

First reported use of a laser to treat diabetic retinopathy. Still widely used to treat abnormal blood vessel growth in diabetes, the laser has prevented blindness in many thousands of patients worldwide.

#### 1990

Introduction of the excimer laser to correct myopia (nearsightedness) and astigmatism (blurred vision due to an irregular-shaped cornea or lens inside the eye). This laser "evaporates" tissue in a controlled way, allowing the cornea surface to be sculpted into a new shape.



Early excimer laser. Summit Medical Technologies. Available at: commons.wikimedia.org/wiki/File:Excimer\_laser\_Summit.jpg

#### 1990

Computerized visual field analyzers become widely available. These machines improve the precision of measurement of peripheral (side) vision. This means physicians can more easily detect early vision loss from glaucoma and its progression.

#### 1991

LASIK surgery is performed for the first time. This procedure is commonly used for vision correction today and involves creating a partial thickness flap in the cornea, then using an excimer laser to reshape the cornea in the bed of the flap before replacing the flap into position. This marked the beginning of the end of eyeglasses and contact lenses for thousands of people across the country.

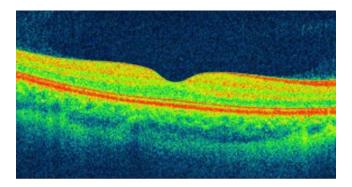
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# 1993-2006

#### 1993

Optical coherence tomography (OCT) machines become commercially available. These machines use a low-powered laser to optically image the retina and optic nerve noninvasively. This allows accurate rapid detection of abnormalities within the retina from the early stages of wet macular degeneration, diabetic retinopathy, and glaucoma.



View of normal retina with OCT. Eyeguru.org. Available at: eyeguru.org/essentials/interpreting-octs/

#### 1996

Adrenergic agonist drops are introduced for intraocular pressure management. They work by increasing the flow of fluid out of the eye, thus lowering intraocular pressure.

#### 1996

Prostaglandin analogues are first introduced as drops for glaucoma treatment. They work by increasing the flow of fluid out of the eye, thus lowering intraocular pressure. Together with adrenergic agonists and beta blockers, prostaglandin analogues form the mainstay of medical (drop) management of glaucoma today.

#### 2001

The selective laser trabeculoplasty (SLT) procedure is approved for glaucoma treatment. Unlike earlier laser glaucoma procedures, SLT does not produce scarring, and therefore can be used more widely in glaucoma treatment.

#### 2005

Anti-VEGF (vascular endothelial growth factor) medication becomes available, which means that, for the first time, people with wet age-related macular degeneration (AMD) can have the disease arrested, often with improvement of vision. The drugs require regular retreatment to remain effective and must be given by injection into the eye.



Lucentis (ranibizumab injection). Available at: <a href="https://www.lucentis.com/hcp/wamd/dosing-and-administration/summary.html">www.lucentis.com/hcp/wamd/dosing-and-administration/summary.html</a>

#### 2006

Lamellar corneal transplants are developed to speed recovery and improve visual outcome. These procedures involve selectively replacing only the layer(s) of the cornea which are diseased through techniques that split the cornea's layers apart during surgery.

# 2010–2022

#### 2010

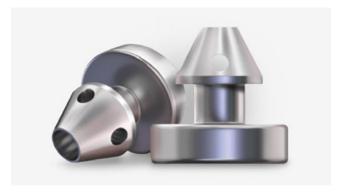
Introduction of the femtosecond laser. This laser can be used to create incisions in the cornea and lens with great precision and has the potential to further improve the outcome of cataract and other eye surgery.

#### 2015

Anti-VEGF drugs are introduced for the treatment of diabetic retinopathy and retinal vein occlusion. They provide significantly better visual outcomes than laser alone.

#### 2015

New generation micro-implants are developed for glaucoma. These devices (stents) are tiny tubes of various designs which are implanted within the fluid drainage meshwork in the front chamber of the eye. They allow excess fluid to be drained from the eye internally without the need of external drainage. This is much less invasive than current types of glaucoma surgery (trabeculectomy and setons), and these promise fewer side effects.



iStent inject® W Glaukos. Available at: www.glaukos.com/enca/ glaucoma/products/istent-inject-w/

#### 2016

Corneal crosslinking is developed to treat people with keratoconus, a condition in which the cornea (the surface of the eye) becomes weak, thin, and irregularly shaped. Crosslinking uses ultraviolet light and riboflavin to make the cornea more stable, significantly lessening the progression of the disease.

#### 2017

Introduction of a gene therapy to treat a hereditary retinal disease. This revolutionary approach offers hope that vision loss will be slowed or prevented for those who have some types of genetic retinal diseases.

#### 2020 to 2022

New anti-VEGF drugs are introduced that reduce the number of injections required for the treatment of AMD and diabetic macular edema, alleviating the treatment burden for patients and their caregivers.

For more on innovations in ophthalmology, please visit seethepossibilities.ca.





# A More Cost-Efficient Retinal Disease Therapy Isn't a Compromise on Quality

**DENISE DEVEAU** 

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here are many things that come with age, including the risk of vision loss. Not only does it significantly hamper daily routines and quality of life, but it can also lead to other life-altering conditions such as depression and injuries from falls. It's not uncommon for older people to receive the news that they're suffering from age-related macular degeneration (AMD). Depending on the type, the decline can be moderate or severe.

According to the Canadian Council of the Blind, AMD is the leading cause of vision loss of people over 55, affecting 2.5 million Canadians. Most sufferers of AMD are diagnosed with the dry type. However, 1 in 10 dry AMD cases advance to wet AMD, a more serious condition in which patients can completely lose their central vision.

Retinal disorders are increasingly affecting the vision of millions of Canadians and the sustainability

# "Reducing costs is a very important issue for the health care system and society as a whole."

DR. MARC SAAB

of the health care system in general. Fighting Blindness Canada reports that as the population ages, the number of people living with vision loss is expected to double by 2032. As the number of people living with vision loss continues to grow, so will spending on health care.

There are different anti-VEGF (anti-vascular endothelium-derived growth factor) biologic treatments available to patients, however. Dr. Marc Saab, ophthalmologist and vitreoretinal surgery specialist, believes that biosimilars have emerged as a sustainable option for retinal vascular disorders and likens biosimilars to the concept of generic drugs. "In simple terms, generics use a chemical molecule," he says. "Biosimilars are very similar but not exactly the same as the reference biologic molecule as they are produced from living cells, and deliver similar efficacy, quality, and safety as the original at a lower price point." This new option in vision care, he explains, is evaluated against the same rigorous regulatory standards used for all other biologic drugs.

Having incorporated biosimilars into his practice a year ago, Dr. Saab says he performs several injections a week – a vast majority of which are used to treat wet AMD.

#### AMD can appear suddenly and progress rapidly

"With conditions such as wet AMD, central vision decreases progressively," explains Dr. Saab. "Central vision is essential for reading and recognizing faces, shapes, and colours. Over time, patients can lose their autonomy as they won't be able to read, watch movies, do sports, or drive."

A major challenge is that AMD can appear suddenly and deteriorate rapidly. Patients might wake up one morning with a change in their vision or find that straight lines suddenly look distorted. They may see blurry areas or dark spots, have difficulty seeing details in low light, or be more sensitive to bright light.



**Dr. Marc Saab, ophthalmologist and vitreoretinal surgery specialist**PHOTO: **THE AMERICAN SOCIETY OF RETINA SPECIALISTS** 

Because wet AMD can progress rapidly, monitoring and early diagnosis are critical, cautions Dr. Saab. "Deterioration can happen within a matter of days," he says. "If left too long, the scarring will prevent the possibility of improvement. An early diagnosis can lead to a better prognosis."

Before biologics there was no treatment for reversing wet AMD, he notes. "Options included injections or laser treatments, none of which improved vision," he says. "They only stabilized the condition for a limited time. The first time we saw improvements was in 2006 when biologics were used for treating wet AMD. It was a new era in the treatment of this blinding condition."

With the emergence of biosimilars, we are entering a new era for vision care. Lowering treatment costs and repurposing the funds to other areas can be beneficial to patients, Dr. Saab adds. "Reducing costs is a very important issue for the health care system and society as a whole," he says. "If we can be more cost-efficient in treatment, we can expand research to cover other diseases."



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# Book an eye exam today.



# **GetEyeWise**

A pledge to raise public awareness about eye health and vision care

**DR. MARTIN SPIRO** 

President, Canadian Association of Optometrists

s we commemorate the 80th anniversary of the Canadian Council of the Blind, it's an opportune moment to reflect on both achievements and challenges within our field. Over the decades, the scope of optometry has evolved significantly. What began as merely dispensing glasses has expanded to encompass detecting, preventing, and treating vision issues, as well as identifying indicators of systemic diseases. The old adage "two little windows of the soul" resonates more deeply than ever, providing insights into both our internal and external environments.

Recent medical breakthroughs and technological advances are ushering in new possibilities for our profession and, hopefully, enhancing vision care accessibility for everyone in Canada. Yet, even with advancements in practice conditions and access, achieving healthy eyes and clear vision across the Canadian populace hinges on regular, comprehensive eye exams. Integrating eye care into the healthcare routines of all age groups, from toddlers to seniors, is crucial.

Despite Canadians highly valuing their eyesight and fearing its loss, there is a prevalent lack of awareness regarding the necessity of regular, comprehensive eye exams. Many individuals often overlook the importance of thorough examinations for early detection. Most sight loss is preventable with early intervention, making education about the critical role of regular eye care essential.

A 2022 survey revealed a telling statistic: 37% of respondents who had not seen an eye care professional in over two years did so because they believed there was nothing wrong with their vision.

Additionally, the survey found that men in Canada are less likely than women to prioritize eye health.

As May marks Vision Health Month, our community is uniting to boost public awareness about eye health and vision care through a simple yet potent message: "GetEyeWise"!

The "GetEyeWise" initiative underscores the fact that many serious eye conditions do not present obvious symptoms initially.

Waiting for symptoms to appear can expose individuals to significant risks, particularly within an aging population, those engaging in increased nearwork, and amidst a myopia epidemic among children.

By championing the "GetEyeWise" campaign, we also advocate for modernizing vision care benefits with the insurance industry, establishing a national eye care strategy at the federal level, and embracing beneficial new technologies.

Let's convey this message to our elected officials to expedite the passage of <u>Bill C-284</u>, paving the way for a national strategy that supports public awareness and advocacy for healthy eyes and clear vision. This is our vision for all Canadians, for life.



'Online survey of 2003 Canadians aged 18+ was completed between June 10 and June 21, 2022, using Leger's online panel conducted on behalf of the Canadian Ophthalmological Society and the Canadian Association of Optometrists.



A woman acts as a sighted guide, assists a man in dark sunglasses and holding a white cane to navigate a pedestrian crosswalk.

# The Vital Role of Client Care Navigation

SHANE GUADELOUPE
PHOTOS: VLRC PHOTO LIBRARY

magine that after several mishaps – like getting burned while making a grilled cheese sandwich, stumbling over a curb, and buying the wrong dog food due to the hard-to-read packaging – you're diagnosed with a form of uncorrectable vision loss.

Feeling overwhelmed, what do you do? Who do you turn to for guidance?

Enter the Client Care Navigators at Vision Loss Rehabilitation Canada (VLRC). They function as a source of guidance and support for Canadians – adults, children, and their families – experiencing the challenges of visual loss. As a non-profit, national health care organization, VLRC's mission is to provide high-quality, integrated, and accessible rehabilitation and health care services that enable Canadians impacted by vision loss to live the lives they choose.

# Communicating the value of Navigators to clients

The health care system can be bewildering, especially for people with vision loss. The term "Navigator" may sound confusing to new clients. Therefore, VLRC's Navigators take time to explain their role during the initial meeting. They collaborate with the client to determine the services needed to accomplish their goals. This emphasizes the significance of the Navigator's role in ensuring

timely access to services. Even returning clients benefit from Navigators' expertise, dispelling misconceptions and guiding them through available options.

"Our Navigators are more than just a support system; they're catalysts for change," explains Jen Urosevic, President and CEO of VLRC. "They play a vital role in connecting clients – whether new or returning – to services, support systems, and assistive technology devices."

# Success story: empowering dreams

Over the years, Tamara Hladuniw, a Navigator and Certified Vision Rehabilitation Specialist, has made a difference in countless lives during her 26-year tenure with VLRC. One young adult, grappling with sudden vision loss, remains etched in her memory

"He had been preparing to attend post-secondary education but felt disheartened, fearing that his dreams were slipping away," Hladuniw recounts. That's when she stepped in.

Hladuniw orchestrated timely VLRC services, including low vision and assistive technology assessments, along with mobility training. Additionally, she connected him to mental health counselling and school resources, ensuring a smooth transition to higher education.

"As a result, he was able to confidently pursue his studies, knowing that VLRC and our community partners would be there for him," says Hladuniw.

# Three core goals of Client Care Navigators

#### 1. Timely guidance

Navigators' primary mission is to provide clients with clear directions. Need rehabilitation services? Wondering about community programs? Navigators' expertise ensures that clients find the right support.

#### 2. Comprehensive assessments

Navigators wear multiple hats intake assessors, risk evaluators, and goal-setters. Whether it's an in-person meeting, a phone call, or a virtual interaction, Navigators adapt. Their initial intake assessment gathers crucial health care information. Risk assessments identify priority clients - those facing job loss, safety concerns, or academic challenges. Flexibility is key; Navigators tailor their methods and use language interpreters for assessments in any language.

#### 3. Seamless transitions

Accessing health care services can be daunting. Navigators bridge the gap between internal VLRC staff and external health care providers, creating a seamless continuum of care. Hospitals, rehabilitation centres, and long-term care facilities are all connected through the Navigators' diligent efforts. If internal resources aren't enough to attain a client's goals, Navigators will make external referrals to other health care disciplines.



Jen Urosevic, President and CEO of Vision Loss Rehabilitation Canada (VLRC)

# Continuous learning: Redefining vision rehabilitation

Investing in staff development lies at the heart of VLRC's success.

"All of our specialists are committed to continuous learning and professional development," Urosevic proudly shares. "For instance, recently a group of our Occupational Therapists participated in a workshop at Queen's University, delving into low vision aids, technology, orientation and mobility aids, and independent living skills. Collaborating with the students, they explored inventive ways to support individuals with vision loss and to enhance their ability to deliver top-notch, client-focused care."

In the intricate tapestry of vision loss, Navigators shine as guiding stars with their dedication to empowering clients toward independence. One client at a time, they redefine the landscape of vision rehabilitation.



### Reflecting on the Canadian Council of the Blind's Legacy

This year, the Canadian Council of the Blind celebrates being the Voice of the Blind™ in Canada for 80 years. From fostering recreation, education, and awareness to driving impactful research and advocacy, the organization's ongoing impact is undeniable.

#### TANIA AMARDEIL

n 1944, amidst the challenges of wartime Canada, a small group of visionaries came together with a singular mission: to illuminate the path toward a brighter future for people who were blind or partially-sighted. From those humble beginnings, the Canadian Council of the Blind (CCB) was born, driven by a vision of empowerment and inclusivity. Today, as the non-profit celebrates 80 years of tireless advocacy and transformative impact, the CCB stands as a

testament to the enduring power of community and resilience. From its roots in enhancing the quality of life for individuals with vision loss through awareness, advocacy, socializing, sports, and health promotion, the CCB has grown into a multifaceted force, embracing peer mentoring, pioneering research, and an array of transformative programs and initiatives that reflect its dynamic evolution over the past eight decades.

#### Origins and evolution: the birth of the CCB

The CCB traces its roots back to the collaborative efforts of 10 individuals living with vision loss in Toronto. Initially focused on advocating for a permanent pension system for people living with blindness, they soon recognized the potential to foster national recreational opportunities for people who were blind or partially-sighted.

This spirit of collaboration led to the formation of the Inter-Provincial Council of the Blind in 1944 (originally made up of the Manitoba League of the Blind and the London Association of the Blind of Ontario), which evolved into the CCB in 1946. By 1950, the CCB was officially chartered and incorporated, and by 1954 it had secured representation in every Canadian province. Over the years, its membership grew steadily, reaching over 70 local chapters from coast to coast to coast today.

While recreation and fellowship remain core aspects of the CCB's mission, its scope has expanded to include advocacy, outreach, training, and research, reflecting its dynamic evolution over the years.

#### Synergies and support: the CNIB's early role

While the CCB was founded independently as a grassroots organization by individuals who were blind and partially-sighted seeking to advocate for their rights and improve their quality of life, it initially garnered support from Canada's service organization – the Canadian National Institute for the Blind (CNIB).

"The CNIB financed the CCB's activities, including travel, meetings, and conferences," writes Euclid Herie, past CNIB President and CEO, in his book *The Journey to Independence: Blindness—The Canadian Story.* "Gradually, the CCB acquired national staff who were funded by the CNIB and who, until 1985, held CNIB employee status."

Established in 1918 to assist servicemen who had become war-blinded and who were facing unemployment and poverty, the CNIB coordinated services and advocated for Canadians who were blind, supporting those who were "[slipping] through the cracks while jurisdictions argued over who should take care of them," writes Herie. "It has been a long journey from the period in Canadian history when blind people were relegated to poverty, derision, pity, abuse, and social conditions that, with few exceptions, left them with a bleak promise for the future. What made the journey possible for many blind Canadians was the development of [...] the CNIB."

While both organizations share a commitment to the community of blind and partially-sighted people, the CCB emphasizes grassroots empowerment and independence. "From the very beginning, the CCB created opportunities to gather socially throughout Canada, learning from each other and expanding horizons," says Jim Sanders, Honourary Executive Director of the Sir Arthur Pearson Association of War Blinded and Past President and CEO of the CNIB (from 2001 to 2009).

Operating locally with chapters nationwide, the CCB prioritizes representation and leadership by individuals who are blind, distinct from the CNIB's broader service model. This consumer-led approach has defined the CCB's evolution and impact, fostering a community-driven movement for Canadians who are blind or living with sight loss.

# **Empowering ownership: the distinct identity of the CCB**

The CCB is distinct in its governance structure, being led and operated by individuals who are blind and partially-sighted. The CCB is the Canadian Council of the Blind, not for the blind – a distinction that people sometimes miss. By contrast, the CNIB is the Canadian National Institute for the Blind.

"That historic evolution and the philosophy of 'we, the blind, speaking for ourselves' led to the so-called consumer movement," writes Herie. "To the uninitiated, the two prepositions 'of' and 'for' have taken on a new significance never to be reversed. An organization 'for' the blind is generally run by well-meaning sighted people, while an organization 'of' the blind is exactly that."

"The CCB's president and board of directors all have lived experience of sight loss," says Louise Gillis, Past President of the CCB (from 2010 to 2021), who focused on revitalizing the Nova Scotia division, expanding CCB membership, and advocating for eye health initiatives to prevent blindness during her tenure and who is still involved with the CCB today as an advisor to the board and member of various committees, including the advocacy committee, the membership committee, and a range of provincial and federal accessibility boards. "The CNIB, meanwhile, is here to serve the community through vision rehab services. It has not been as involved in health care or advocacy as we at the CCB have."

# Recreation redefined: enriching lives through CCB initiatives

The CCB has long recognized the transformative power of recreation, both as a means of empowerment for its members and as a tool for social rehabilitation. Since its inception, the organization has prioritized recreational activities, spearheaded by its dedicated Recreation Committee, which was established in 1949. Initially offering concerts and games like cribbage



Jan. 1948 – Members of the 'Sunshine Group' of the New Westminster White Cane Club are shown displaying remarkable skills developed through their specialized blind activities – sewing, leather work, knitting, and weaving.

and bingo, the scope of activities has expanded significantly over the years. From bowling and dancing to literary groups and golfing, local CCB chapters have embraced a diverse range of pursuits. Today, the offerings include curling, sailing, baseball, dragon boating, downhill and cross-country skiing, dart throwing, archery, running, cycling, and more, catering to varied interests and abilities.

Additionally, joint summer camps with the CNIB – initially in Ancaster, Ont., and later on Lake Joseph in Muskoka and in Atlantic Canada – have provided opportunities for socialization and personal growth in a supportive environment. Recreation remains a cornerstone of the CCB's mission, enriching the lives of its members across Canada.

# Charting autonomy: the CCB's journey beyond CNIB support

At its inception in 1944, the CCB grappled with the challenge of financial sustainability. Initially reliant on member club support, the CCB turned to the CNIB for assistance. In the early 1980s, however, the CNIB began envisioning a future of financial independence for the CCB, and the dynamics shifted. The CNIB gradually withdrew funding from local CCB divisions, prompting the CCB to pivot toward independent fundraising and to approach the federal government for financial assistance. In 1985, a new CCB/CNIB financial agreement was finalized and signed.

This transition marked a new era for the CCB, not only in achieving financial autonomy but also redefining its core focus. According to Sanders, this transition stemmed from a fundamental shift in the role of consumer organizations like the CCB. Initially, the CCB served primarily as a community hub, fostering social connections and facilitating recreational activities. However, as societal dynamics evolved, so did the mandate of the CCB. The

burgeoning influence of political discourse and the growing emphasis on advocacy prompted the organization to adapt its focus.

### From recreation to activism: the CCB's dynamic evolution

As societal perspectives shifted, the CCB embarked on a transformative journey, transcending its traditional recreational focus to become a proactive advocate for people living with vision loss. This evolution, which mirrored broader societal changes, saw the organization prioritize initiatives aimed at raising awareness and advocating for policy reforms. Issues such as accessibility, employment rights, and health care became central to its agenda, reflecting a steadfast commitment to addressing the multifaceted needs of its community. Navigating this transition, the CCB reaffirmed its relevance by empowering those who are blind or partially-sighted through advocacy and engagement.

From its inception to the present day, the organization has displayed remarkable adaptability, swiftly addressing challenges and meeting members' evolving needs. This agility is evident in its advocacy efforts and the diverse array of programs tailored to its members. "We can pivot quickly to suit the needs of our membership," says Jim Tokos, National President of the CCB. "We also involve a lot of our members in committee work, and that's how we get feedback from them on where to direct our advocacy work."

# **Driving progress: the CCB's member-centric** approach to leadership

The CCB's membership-driven ethos is central to its collaborative approach and organizational identity. Tokos believes strongly in empowering board members to take on greater leadership roles and initiative, fostering a sense of ownership and collective responsibility. "What really makes me tick



1967 - A CCB-donated mobile eye clinic (MEC) extends crucial eye care services to underserved populations in India.

is encouraging board members to get involved and contribute," he says. "I like to take a step back and to empower our team and see them progress. That way, everybody feels like they own a piece of the pie." The CCB's grassroots approach, facilitated by its nationwide network of local chapters, also enhances its adaptability and responsiveness to member needs.

The establishment of the national Membership Committee in 1976 underscores the organization's commitment to growth and inclusivity. Tokos emphasizes the importance of nurturing future leaders within the CCB, providing equal opportunities for advancement and continually seeking fresh perspectives to drive the organization forward. "Everybody has equal opportunity if they want to move up," he says. "We're always looking for new leaders."

#### Beyond borders: the CCB's international impact

Part of the CCB's transformation during the 1980s, amidst its separation from the CNIB, included the cultivation of robust partnerships with like-minded organizations, both domestically and abroad. This strategic shift proved pivotal in amplifying the CCB's advocacy efforts and extending its influence globally.

The CCB had been actively engaged with the World Blind Union since its inception in 1984, as had the

CNIB, with both being inaugural members. Over the years, the CCB continued to forge collaborations worldwide. Notably, in 1967, the CCB raised funds to purchase a mobile eye clinic (MEC) to combat blindness in India, extending crucial eye care services to underserved populations. The MEC went to China twice around 2016 and was essential in helping the local community to set up remote clinics in the Hebei province. Having operated mostly in the Ottawa Valley region in Canada, the MEC program is poised to operate across Ontario, particularly targeting schoolaged children and seniors not just in urban centres but in areas with limited access to traditional eye care facilities, including rural and remote communities. Staffed with optometrists and trained professionals, these clinics provide essential eye care services such as full eye examinations, vision screenings, and ophthalmic referrals, along with providing eyeglasses where there's an economic need, often in collaboration with local organizations, school boards, seniors' centres, and health care providers.

In 1974, the CCB launched its 30th Anniversary Project, exceeding its goal to finance 1,000 sight-restoring cataract operations in Bangladesh. Collaborating with local partners, the CCB also contributed to the construction of the female wing

of an eye hospital in Bangladesh, bolstering health care infrastructure and enhancing access to services, particularly for women.

Throughout the 1970s and 1980s, the CCB continued its overseas efforts, including a partnership with Operation Eyesight Universal to address curable blindness in Kenya. Domestically, the CCB advocated for eye health education, promoted eye examinations, and facilitated access to visual aids, striving to ensure equitable eye care for all.

# Advancing visionary advocacy: the CCB's impact on eye health

In recent years, the CCB's advocacy work has been instrumental in shaping eye health care legislation, research, and treatments. As the field of eye health care experiences remarkable progress driven by technological advancements and innovative therapies, the CCB has remained at the forefront of ensuring inclusivity and accessibility in eye care services.

Breakthroughs in surgical techniques, diagnostic tools, and pharmaceutical therapies have revolutionized eye care, offering patients more precise and effective solutions. For instance, advancements in treatment for age-related macular degeneration (AMD) and other retinal diseases have reduced injection frequency, promising improved outcomes. These advancements underscore the ongoing commitment of researchers, clinicians, and industry leaders to continually push the boundaries of what's possible in preserving and restoring vision.

Throughout it all, the CCB has played a pivotal role in advocating for the needs and rights of individuals with vision loss and raising awareness about accessibility in health care. During Gillis' presidency, the CCB influenced government policies like the Canada Accessibility Act, promoted a national eye care strategy, and established partnerships with pharmaceutical companies working in the eye care space.

Additionally, the CCB emphasizes proactive vision care for individuals without vision loss, advocating for regular eye examinations and preventive measures to maintain optimal eye health throughout life and prevent blindness. "Even though we're an organization of the blind, we're always advocating for people to look after their eyes and make sure they get their eyes checked regularly," says Tokos.

By championing the voices of those affected by visual impairment and promoting vision health for all, the CCB continues to be a driving force in shaping the future of eye care in Canada.

# Forging a new frontier: enhanced advocacy through research

The CCB's recent expansion of its advocacy efforts is bolstered by a new focus on research. The organization has been instrumental in promoting research initiatives focused on addressing the specific needs and challenges faced by individuals with visual impairments, contributing to a more comprehensive understanding of eye health issues and innovative solutions.

In the past six years, the CCB has actively pursued research endeavours independently and through strategic partnerships, notably with Fighting Blindness Canada, the largest charitable funder of vision research in Canada. Spearheading this initiative is Michael Baillargeon, the CCB's Senior Manager, Eye Care Initiatives. Baillargeon initiated the organization's inaugural research study in 2019, examining the needs for accessible technology of individuals who are blind or partially-sighted. Recognizing the significance of this endeavour and the need to expand the CCB research effort, Baillargeon brought on Dr. Keith Gordon, former Vice-President of Research at CNIB, as the CCB's Senior Research Officer.

Since then, Baillargeon and Dr. Gordon have conducted six pivotal studies, including the Cost of Vision Loss and Blindness in Canada (2021), an addendum focusing on the pandemic's impact on the cost of vision loss and blindness (2021), and two surveys assessing the pandemic's effects on those with vision loss (2020, 2022). Additionally, they produced a Report Card on Vision Health in Canada (2022) and surveyed Ontario residents who are blind or partially-sighted on their experience with the Accessible Devices Program.

The data generated by these studies has been used to support robust advocacy campaigns on a number of fronts, by both the CCB and allied organizations.

#### Driving change: the CCB's advocacy journey

Throughout its history, the CCB has been a steadfast advocate for a range of causes, from enhancing educational facilities for children who are blind or partially-sighted to championing legislation supporting Canadians living with vision loss, including securing pensions and special assistance allowances. Other advocacy initiatives have included advocating for accessibility features on Canada's banknotes, addressing pressing employment issues facing Canadians living with vision loss, and advocating for improved accessibility of eye care treatments and medications. Its efforts have resonated across Canadian society, leaving an indelible mark.



The Canadian Council of the Blind's 3rd Annual Convention, Hotel Georgia, Sept. 8-10, 1947, Vancouver, B.C.

Under the leadership of John Rempel, who served as National President from 1998 to 2004, the CCB notably advanced transportation accessibility, reinforcing its commitment to inclusive mobility. Additionally, its pivotal role in the 2019 passage of the Accessible Canada Act, a landmark legislation aimed at fostering equality and inclusion for Canadians with disabilities, underscored its dedication to inclusivity and advocacy.

#### Advancing vision health legislation: Bill C-284

More recently, the CCB collaborated with the federal government and other stakeholders to support Bill C-284, "An act to establish a national strategy for eye care," a Private Member's Bill introduced by the Honourable Judy A. Sgro, MP for Humber River-Black Creek, which aims to establish a national strategy

for eye disease prevention, treatment, and vision rehabilitation. The bill was introduced in the House of Commons in June 2022, where it underwent three readings, and on October 25, 2023, it passed with unanimous support from all parties. On October 26, the bill received first reading in the Senate. Under the sponsorship of Senator Mohamed-Igbal Ravalia, the bill is undergoing its due processes in the Senate and is expected to pass, receiving Royal Assent by mid-June 2024. Bill C-284 underscores the CCB's ongoing commitment to advocating for the needs of its members and fostering a more inclusive society. "Bill C-284 wouldn't be where it is today if it weren't for the CCB and the amazing work they did by connecting people and continuing to lobby all the Members of Parliament," says Sgro.



From pharmaceutical access to transportation to employment equity, the CCB's advocacy work encompasses a wide array of issues, reflecting its dedication to breaking down barriers and ensuring equal opportunities for all. "Advocacy is like a tree with many branches," says Tokos. "We advocate for the needs of our members."

Guided by the principle of "nothing about us without us," the CCB continues to strive for a more inclusive society where everyone can fully participate and thrive.

#### **Reforming Ontario's Assistive Devices Program**

In other recent advocacy efforts, the CCB has been actively working toward reforming Ontario's Assistive Devices Program (ADP). This program is a vital resource, offering partial funding for essential assistive

devices crucial for individuals with long-term physical disabilities, including those with vision loss.

Responding to user feedback expressing frustration with aspects of the program's functionality, such as its ability to keep pace with evolving technology and provide prompt reimbursement for assistive devices, the CCB collaborated with a group of stakeholder organizations to form the Vision Loss ADP Reform Working Group. With the cooperation of vision stakeholders, the CCB conducted a comprehensive survey in 2021 of individuals living with vision loss to better understand their experiences with the ADP.

The findings, coupled with a supplementary survey of ADP authorizers and vendors, informed a detailed report outlining key recommendations. This report was presented to the Ontario Ministry of Health and ADP management. Presently, all stakeholders

are working collaboratively to implement necessary changes and optimize the program's efficacy.

The CCB's commitment to this endeavour highlights its dedication to enhancing accessibility and support within the vision loss community. Through robust research and advocacy, the CCB is effecting tangible improvements in the lives of individuals who are blind or partially-sighted.

### Bridging the digital divide: Get Together with Technology

As technology advanced in the late 20th and early 21st centuries, the CCB adapted its programs to meet changing needs. The proliferation of computers and smartphones – which forever transformed the way we communicate, access information, and interact with technology – necessitated training for individuals living with blindness or vision loss on their usage. With the rise of accessible software and assistive devices, including smartphones, tablets, and computers, individuals with vision loss gained increased access to these technologies.

Out of this necessity, the Get Together with Technology (GTT) program was born in 2011. Founded by Kim Kilpatrick and Ellen Goodman, GTT offers technology training by and for people with vision loss, ensuring access to educational, employment, and recreational opportunities in the digital age. Recognizing technology's potential to empower those with vision loss, GTT provides information, resources, and a supportive network to help individuals with vision loss gain competence and confidence in using accessible technologies. "It's an outstanding program that has been immensely successful," says Tokos.

Over the years, GTT has trained hundreds of people living with vision loss, including youth, seniors, and those with multiple disabilities. As technology continues to evolve, so does the GTT program, ensuring that individuals remain equipped with the skills needed to navigate the ever-changing digital landscape.

### Changing perceptions: the evolution of White Cane Week

White Cane Week, an annual public awareness campaign initiated in 1946, has evolved to meet the changing needs of the community of people who are blind or partially-sighted. Initially launched in collaboration with the CNIB to raise public awareness about blindness, the focus shifted in subsequent years to highlight the achievements and capabilities of people living with blindness. By 1948, the campaign centred on advocating for improved legislation for Canadians living with blindness.

White Cane Week was ceded completely to the CCB in 2003. Under the leadership of Harold Schnellert, who served as National President of the CCB from 2004 to 2010, White Cane Week expanded substantially. Schnellert emphasized publicizing the abilities of people who were blind and partially-sighted, reframing the narrative to focus on empowerment rather than disability. Since then, White Cane Week has continued to grow, featuring nationwide events and garnering extensive press coverage.

# Igniting engagement: the White Cane Week Experience Expo

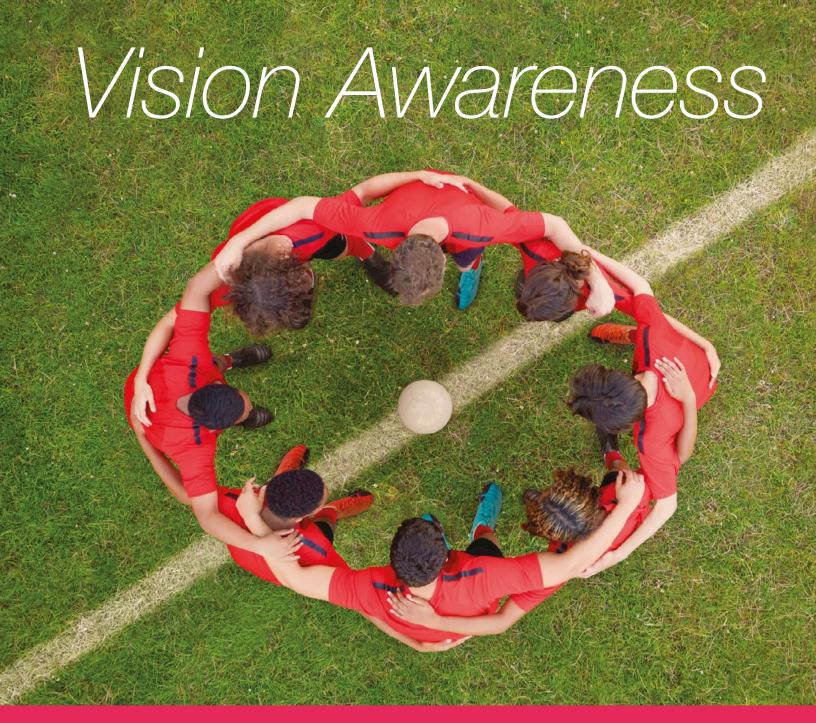
The CCB's Experience Expo, initiated by its Toronto Visionaries Chapter in 2015 and taking place annually during White Cane Week, serves as another significant initiative to amplify awareness and understanding of blindness-related issues. The Expo brings together people with vision disabilities along with sighted friends to explore the experience of living with blindness and low vision.

The Experience Expo is Canada's sole exposition and consumer show for people with vision loss. The interactive, hands-on exhibition features dozens of exhibitors, products, and services covering every aspect of living with vision loss – including from leading tech companies, stakeholder organizations, agencies, service providers, and blind sport organizations and clubs. Besides the consumer show, the Experience Expo also includes the Expo Vision Forum (a panel discussion presented by the CCB) and a celebratory community social and dinner for all guests and exhibitors.

"It feels fantastic to come together face to face as a community, to share information, to see the range of supports and services available to those with vision loss, to see what's possible, and to celebrate our resilience in the face of adversity," says lan White, President of the CCB Toronto Visionaries Chapter. "It's what the Expo is all about!"

# Engaging with the CCB community: past and present

The CCB Outlook, the official quarterly magazine that served as the voice of the CCB for nearly four decades, debuted in January 1948 with an initial circulation of 2,200 copies. Widely distributed to individuals, libraries, medical offices, and beyond, the magazine was a vital communication tool with the CCB membership and the public alike. Over time, it expanded in content and popularity, was offered in braille, print, and recorded versions, and circulated globally to over 30 countries. Its diverse content covered CCB governance issues, news updates, human interest stories, special events, poetry, jokes, and discussions on various topics.





At Bayer, we are passionate about patient-centred care, creating a network of worldwide expertise, and advancing knowledge through collaboration. Together, we can help people living with retinal disease accomplish their dreams.



Photographer: David Katz

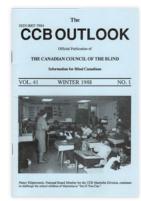
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By the decades - cover designs of The CCB Outlook publication from 1948-1988.

Columns like "Friendship Corner" and "President's Commentary" provided personal touches amidst reports on research and contemporary issues, fostering a sense of community.

Today, the tradition continues with *White Cane Magazine*, which focuses more broadly on issues related to blindness, visual impairment, and disability. Covering personal narratives, news stories, expert interviews, technology reviews, research updates, and advocacy discussions, the magazine remains a vital link within the CCB community, connecting members past and present.

# Bringing together a unified voice: the CCB's leadership in conferences and community collaboration

In recent years, under the leadership of Baillargeon, the CCB has catalyzed a remarkable convergence within the vision health community. Through concerted efforts, the CCB has united key stakeholders, including the Canadian Association of Optometrists, the Canadian Ophthalmological Society, Fighting Blindness Canada, Vision Loss Rehabilitation Canada, and the CNIB, amplifying their collective voice and bringing them together to speak as one on a number of critical issues.

This newfound collaboration and partnership has paved the way for the CCB to host three pivotal conferences annually, demonstrating its unwavering dedication to fostering dialogue and action among key stakeholders. "The CCB has evolved into a true powerhouse," remarks Sanders. "It's a force to be reckoned with in this country."

In 2023, the CCB orchestrated a series of impactful gatherings, including a conference spotlighting innovative sight-saving treatments during Vision Health Month, a forum providing an update on the progress of the Vision Loss ADP Reform Working Group, and a critical assessment

of the current state of vision health in Canada based on the CCB Report Card on Vision Health.

The momentum continues into 2024 with the successful February conference during AMD Awareness Month, which addressed new treatments for AMD and challenges faced by those living with the disease. Thanks to a collaboration with Fighting Blindness Canada and featuring insights from Statistics Canada researchers, the event garnered significant attention and engagement.

Looking ahead, the CCB Vision Health Month Conference in May 2024 promises to be a highlight, focusing on the burgeoning role of artificial intelligence (AI) in vision health. With an emphasis on cutting-edge technologies poised for near-term implementation, distinguished speakers such as Dr. Jutta Treviranus, Dr. Delan Jinapriya, and Jason Fayre will provide invaluable insights into AI's potential impact.

# Honouring heritage, embracing tomorrow: looking forward to the future

Throughout its rich history, the CCB has epitomized the strength found in unity, celebrating the remarkable contributions of its members. From the inception of the prestigious CCB Award of Merit in 1953 to the modern recognition through the President's Award and Person of the Year accolades, the organization continually honours those who tirelessly champion its cause. Under visionary leadership, the CCB has become a driving force in Canada, fostering collaboration across diverse sectors including medicine, rehabilitation, advocacy, and research.

As the CCB commemorates its 80th anniversary, it remains dedicated to its mission of improving the lives of Canadians who are blind and partially-sighted. Looking forward, the CCB stands poised to continue its legacy of hope, inspiration, and support, propelled by the collective efforts of its members, partners, and supporters.



# Canada for over 10 years

#### Patient groups and advocacy 60+ initiatives

Bayer is committed to supporting patient advocacy groups in Canada that help to provide education, awareness, and materials to improve patients' quality of life.

#### Research studies 17+ studies

Bayer is continually investing in Canadian research and Investigator Initiated Research (IIR) to innovate and develop new ways to treat retinal diseases. It's all part of our mission statement: *Health for All, Hunger for None.* 

#### **Academia and fellowships** 70+ institutions

Bayer is investing in Canadian institutions to educate and train new optometrists and ophthalmologists to provide the highest standard of care for eye disease.

#### **Education** 120+ programs

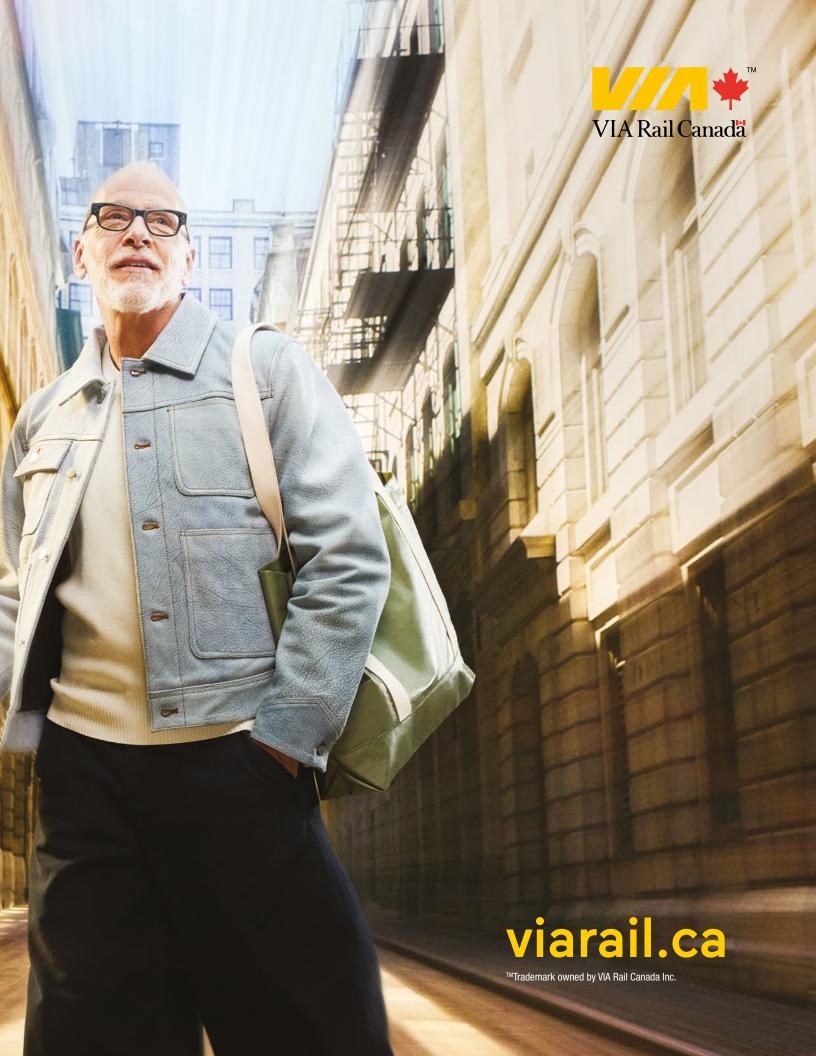
Bayer is dedicated to supporting programs that train Canadian ophthalmologists and clinical staff in new and emerging medicines and treatments to help improve patient outcomes.

#### Conferences and symposia 135+ conferences

Bayer is supporting local and national conferences, to help improve patient care in Canada by providing ophthalmologists with access to the latest science, clinical trends, and experts.







# (a) MacuMira

CANADA'S FIRST CLINICALLY PROVEN AND REGULATORY APPROVED TREATMENT FOR DRY AGE-RELATED MACULAR DEGENERATION



## AMI Unveils Its Exciting Summer of Content



With summer approaching, AMI has lined up a robust programming schedule. With returning favourites and exciting debuts on AMI-tv and AMI+, AMI continues to establish itself as a leader in the offering of accessible content providing a voice for Canadians with disabilities through authentic storytelling, representation, and positive portrayal.

#### May



Postcards From... host Christa Couture (right)

#### Postcards From... returns Wednesday, May 22, at 9:30 p.m. Eastern to AMI-tv and AMI+

Join Christa Couture – award-winning singer-songwriter, non-fiction writer, filmmaker, and member of the disability community – as she embarks on a multisensory journey, revealing a secret side to Canada we taste, touch, smell, see, and hear for the first time. Among the communities Christa visits are Drumheller, Alberta; Dawson City, Yukon; Niagara Falls, Ontario; and Whistler, British Columbia.

#### **June**



By Hook or By Cook's Bruce Cook (centre)

# The Squeaky Wheel: Canada debuts Monday, June 24, at 9 p.m. Eastern on AMI-tv and AMI+

Be loud. Be disabled. Be squeaky. Based on Steven Verdile's popular web publication The Squeaky Wheel, The Squeaky Wheel: Canada is an eight-episode satirical. half-hour news format which pokes fun at the ableist society people with disabilities face every day. Directed by Lucy Belgum and Tobi Abdul, the series stars Graham Kent and Gaitrie Persaud as lead anchors Grant Gewürztraminer and Arianna Salara. The ensemble cast of Margaret Rose, Samantha Wyss, Sivert Das, Wesley Magee-Saxton, and Yousef Kadoura are

on the scene, ready to take on absurd situations and characters, including flipping the script and embodying obnoxious able-bodied/ neurotypical personalities.

# By Hook or By Cook returns Friday, June 28, at 9 p.m. Eastern to AMI-tv and AMI+

Bruce Cook has dedicated the past 10 years to showing others what is possible, performing under the spotlight and proving to himself that his accident happened for a reason. He has accomplished more than he imagined post-injury, establishing a foundation that allows others the opportunity to step outside of their comfort zones. But what about

# A M I

his own? As the spotlights begin to fade and Bruce's life falls into a rhythm, he finds himself conflicted by who he wants to be, who he thought he would be, and who he really is. This season will find Bruce on his way to accepting and coming to terms with who he really is after 10 years in a wheelchair.

#### **July**



# Breaking Character returns Tuesday, July 9, at 9 p.m. Eastern to AMI-tv and AMI+

Breaking Character is the first documentary series to explore the entertainment industry from the perspective of performers with disabilities. It comes at a critical time when the industry has finally started to recognize disability as the missing link of inclusivity. We capture the ups and downs of building careers while also fighting the battle for representation. The message is simple: talent is there; now it's time for the talent to get opportunities. In Season 2, four new faces continue the fight to find a place for themselves and their circle.

#### Mind Your Own Business: Then, Now and Next debuts Friday, July 26, at 9 p.m. Eastern on AMI-tv and AMI+

In this live special, host Kevin Shaw and the business mentors welcome four entrepreneurs from past seasons. They'll reveal how their businesses are doing and take questions from the live studio audience.



Mind Your Own Business host Kevin Shaw

#### **August**

#### Got Game debuts Monday, August 14, at 9 p.m. Eastern on AMI-ty and AMI+

Got Game explores coming of age in a board game café as six youth with disabilities share their stories in a round table discussion while playing inclusive tabletop games. Got Game provides an outlet for youth with disabilities to share their feelings, frustrations, triumphs, ambitions, and general outlook on life with a disability. But it's not about defining these individuals by their disability; it's about recognizing the individualism of these youth aside from their disability.

And don't forget AMI's two live daily shows! Join Dave Brown on NOW with Dave Brown, weekdays at 9 a.m. Eastern on AMI-tv, as he discusses the latest news, entertainment, sports, and current events through a disability lens. Then tune in to Kelly and Ramya, weekdays at 2 p.m. Eastern on AMI-tv and 4 p.m. Eastern on AMI-audio, for interviews and discussions about arts, entertainment, and the lifestyle issues that matter

to you. Both NOW with Dave Brown and Kelly and Ramya are available as podcasts from your favourite podcasting platform.

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

#### AMI.ca has a new look!

This spring, AMI.ca was re-branded as a corporate website. Visitors to the new AMI.ca will find information about careers available at AMI, the annual AMI Scholarship, AMI Research Panel, AMI-tv and AMI-audio schedules, described video guide and popular recipes from Dish with Mary and Four Senses.

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

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

Want to have input into the future of programming at AMI? Join our Research Panel at <a href="mailto:ami.ca/researchpanel">ami.ca/researchpanel</a>.

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

Follow AMI on Facebook
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(@accessiblemediainc).







# Ophthalmology Innovation - Artificial Intelligence Tapping into AI to positively impact eye care in Canada

With all the recent buzz about artificial intelligence (AI) in medicine, you might be wondering how it might be used to support eye care. Ophthalmologist Dr. Fares Antaki shares his perspectives on the potential role of AI technology in the field of ophthalmology.

While still in its infancy, AI has the potential to be integrated into ophthalmologic clinical practice with the goal of supporting three main areas:

#### PATIENT SCREENING



Provide large-scale, low-cost screening for some Big 5 eye diseases, like diabetic retinopathy (DR) and in the future, AMD and glaucoma

Al-assisted screening may help:

- Allow more patients to be assessed for eye disease
- Speed earlier detection of serious eve conditions
- Reduce workload on busy clinics and hospitals, allowing more time for patients who require treatment

Eventually, there's a potential to reinvent eve exams using Al-based tools at every step to: Take patient history Measure visual acuity

Identify eye disease through automated slit lamps and imaging

This could transform the clinic waiting room into a pre-testing space or give ophthalmologists the ability to take care of patients in remote areas



Canadian Société Ophthalmological canadienne

Society d'ophtalmologie

EYE PHYSICIANS | MÉDECINS ET CHIRURGIENS AND SURGEONS | OPHTALMOLOGISTES OF CANADA | DU CANADA

#### DIAGNOSTICS



Assist eye care professionals in making a diagnosis or predicting risk of disease progression with better accuracy

Al models are in development that can help:

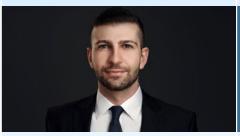
- · Diagnose diseases like glaucoma, AMD, and DR from retinal fundus images
- Identify and follow conditions of the front of the eye such as cataracts, keratitis, and conjunctival conditions

#### **Optometry clinics**

could employ AI models that help detect signs of eye disease and triage patients for referral to their nearest ophthalmologist based on the urgency

#### **Ophthalmology clinics**

could have more advanced clinical decision-making tools (for example, an Al system that considers patient demographics, optic nerve appearance, and visual fields to inform risk of glaucoma or risk of progression)



Dr. Fares Antaki Ophthalmologist, Centre hospitalier de l'Université de Montréal, Montréal, Ouébec

#### TREATMEN'



Advance precision medicine - choosing the best treatment for each unique patient

#### **Cataract surgery**

Al algorithms already allow ophthalmologists to select the best power of intraocular lens for each patient based on their eye dimensions

A smart Al agent is in development that informs the specialist performing anti-VEGF injections whether they need to switch medications or adjust the treatment interval, based on the appearance on imaging and patient's visual acuity

#### Retinal surgery

In the future, AI systems could allow ophthalmologists to determine the ideal surgical technique and post-operative instructions for each patient for the best possible outcome

"I believe we need to build AI systems that are useful for the clinician, for the patient, and for the healthcare system. It's important for us to determine what the bottlenecks are for providing efficient and high-quality care for our patients and using Al to address those issues." Fares Antaki, MDCM, FRCSC

Learn more about Al innovation in ophthalmology, please visit seethepossibilities.ca.

# Overcoming Vision Barriers to Achieve my Dream Career

My lived experience of community support and inclusivity in the optical industry

t six months old, I embarked on a peculiar eye health journey shaped by my diagnoses of astigmatism, nystagmus, and achromatopsia. Looking back, I understand how unconventional it is to spend so much of your childhood visiting specialists. However, while

I was navigating the intricacies of short-sightedness, colour blindness and severe light sensitivity, I know my experience was unique in that I never felt I was treated differently by my family and my peers.

Growing up I had dreams of becoming an optometrist, but I quickly learned that there were limitations to that





**Khalil Musani**Retail Partner at
Specsavers Lawrence Allen Centre

career path, due to my own vision impairment. I didn't let that stop my desire to contribute meaningfully to eye health and the industry. My parents, who never wanted me to feel like I was living in a bubble, challenged me to grow and succeed, and instilled confidence that I could do anything I put my mind to. I still hear the words of my father every day, "The only thing standing in your way is you."

My mother was working at a Specsavers in the UK – the same Specsavers location that showed me so much care when I was fitted for new glasses at 11 years old. It was the care I received during my first fitting that drew me to the company. Marked by my positive eyecare experiences in my adolescence, I began working part-time at that location caring for customers and conducting pre-test screenings.

At that time, I was 16 years old with no retail experience, but Specsavers welcomed and provided me with the training I needed. My time at Specsavers has been transformative. It was inspiring to many people to see my career progression and the opportunities that could exist for me, despite perceived challenges with vision impairment. I found fulfillment in roles that exceeded my initial expectations, and I became an in-store trainer at the age of 19. I started the role shy and unsure how to motivate and train 30 colleagues at



Khalil Musani and his team of opticians and eyecare consultants at Specsavers Lawrence Allen Centre.

once, but it took no time for my passion to take over and drive my success. It's been the journey of a lifetime from then to now.

Mentoring and leading others to share the same passion for quality care and service was my calling, and I gained confidence in the realization that I had found what I was born to do. My journey exemplifies a career at Specsavers, where opportunities to grow feel endless and individuals are supported to feel successful, regardless of their background or challenges.

When opportunity came knocking again, I embraced it and started my very own business as the Retail Partner of Specsavers Lawrence Allen Centre. Becoming a business owner of an optical retail store represented a culmination of my aspirations – to lead my own team and make a tangible impact on eye health outcomes. I have embraced this role thanks to the unwavering support from the Specsavers community and my family.

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My journey
exemplifies
a career at
Specsavers, where
opportunities to
grow are endless
and individuals
are supported to
feel successful,
regardless of their
background or
challenges.

The robust support system provided by Specsavers, both in the UK and Canada, has been central to my success. From mentorship programs to a dedicated retail support team, Specsavers has equipped me with the tools and resources needed to excel on this path. This support extends beyond professional realms, encompassing a culture of inclusivity and camaraderie that fosters personal growth and resilience.

As I reflect on my lived experience so far, my two pieces of advice for individuals in similar shoes to me are: embrace your unique identity, regardless of perceived challenges or limitations, and lean on your support system – people will help you get to where you need to go.

Whatever barrier you might have, I hope you seize opportunities, overcome hurdles and defy expectations. And remember, you are not alone in your journey when you have a great team behind you.

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Specsavers







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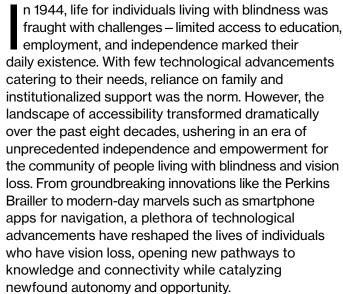




# Shaping a Brighter Future: How Technology Has Revolutionized the Experience of Living with Blindness Since 1944

Over the past 80 years, technological innovations have transformed accessibility, independence, and connectivity for people living with vision loss.

IAN WHITE



The Canadian National Institute for the Blind (CNIB), established in 1918 for blinded World War I veterans, began by running the braille lending library with less than 100 volumes, and offered limited rehabilitation services and a modest residence in downtown Toronto.¹ While national in vision, by 1944 the CNIB was only active in a very limited area of Canada (Southern Ontario), its reach to other provinces being primarily via its braille and talking book service through the mail. As World War II veterans returned home in 1944, there were few government or social supports or services to help Canadians who were newly blind to adapt,

and most people "handicapped" by blindness relied on family to support and care for them.

Blind person using computer with braille keyboard

The first Seeing Eye guide dog school in North America was only established in the U.S. in 1931, so guide dogs would have been fairly rare in Canada just 13 years later (the first Canadian guide dog school was not established until 1985).<sup>2</sup>

The white cane, a wooden stick painted to increase its visibility, first created in 1921 in England, was distributed through the Lions Clubs in 1931 and later by the CNIB, but was not yet universally accepted or known as a symbol of independent mobility for people living with blindness.<sup>3,4</sup>

Literacy, education, and reading material for people living with blindness was relatively scarce. By 1944, the CNIB Library collection had increased to a few thousand titles of hand-transcribed braille books and "talking books" on long-play records, and would send these out to subscribers through the post, with clients sometimes waiting months for a book. Until the 1960s, newspapers and magazines were not accessible in any format, and people living with vision loss relied on volunteers or family members to read to them.<sup>5</sup>

Employment opportunities were limited and people who were blind were often barred from post-secondary education due to their "handicap." Typically, children who were blind would be sent to a boarding school for the blind, institutionalized and segregated from mainstream society, their friends, and their parents.

https://www.guidedogs.ca/our-organization/ Accessed on 2024-04-11

<sup>1</sup> https://www.cnib.ca/en/about-us/our-history?region=on Accessed on 2024-04-11

https://en.wikipedia.org/wiki/White\_cane Accessed on 2024-04-11 https://gttprogram.blog/2020/02/06/white-cane-week-2020-history-of-the-white-cane/ Accessed on 2024-04-11

<sup>5</sup> https://thatallmayread.ca/explore-history/within-living-memory/reading-by-sound/ Accessed on 2024-04-11

Living with blindness in 1944 would have meant living with limitations, exclusion, segregation, and dependence.

But in the past 80 years, there have been many technological breakthroughs that have increased independence, boosted access to literacy, and improved the quality of life for Canadians who are blind. Here are just a handful of examples:



#### The Perkins Brailler (1951)<sup>6,7</sup>

The Perkins Brailler replaced manual and early mechanical braille production, making accessible reading materials more universally available. It became a powerful tool in gaining literacy and education, enabling people who are blind to both read and write braille and to enter the workforce fully literate and independent.



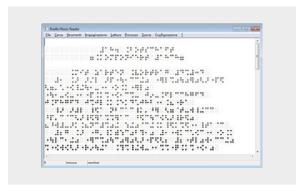
#### Talking books on tape (1950s)8

Clarke & Smith manufactured the first talking book machine, recording audio to a magnetic tape and replacing bulky, cumbersome, multi-volume braille books and talking books on LP. This was a harbinger of books on four-track cassette tape and the DAISY and digital audiobooks we know today.



#### **Closed-circuit television (CCTV)** enlargers (1970s)

Starting in the 1970s, and improving with compact, low-cost, hand-held camcorder technology in the 1980s, CCTVs' zoom function allowed users to increase magnification as needed, while their colour-reversing capability allowed users to increase contrast. Now with up to 64x magnification, a multitude of alternative colour schemes, and built-in optical character recognition (OCR) and synthetic text-to-speech, CCTV video enlargers are one of the most valuable assistive devices for those with low vision.



#### Braille translation software (1976)9

The first braille translation software was developed in the early 1960s, a precursor to the present Duxbury Braille Translator. It was first installed at the CNIB in Toronto in July 1976.

https://en.wikipedia.org/wiki/Frank\_Haven\_Hall Accessed on 2024-04-11

https://www.duxburysystems.com/bthist.asp Accessed on 2024-04-11

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https://www.pathstoliteracy.org/wp-content/uploads/2022/06/perkins\_brailler\_history.pdf Accessed on 2024-04-11 https://thatallmayread.ca/explore-history/within-living-memory/reading-by-sound/ Accessed on 2024-04-11



#### **Braille page embossers (1970s)** and refreshable braille displays (1982)10

First available in the 1970s, braille page embossers, combined with braille translation software, revolutionized braille mass production. In 1982, the first refreshable braille displays were available in the U.S. In 1995, the first release of Duxbury for Windows with output to a refreshable display or an embosser meant any personal desktop computer could translate digital text into braille and conveniently output it for the personal use of people living with blindness.



Kurzweil Reading Machine (1978)<sup>11,12,13</sup>

A merger of three brand-new technologies (flatbed scanner, optical character recognition [OCR],

and a full text-to-speech synthesizer), the Kurzweil Reading Machine was the first machine to convert books and other printed materials into synthetic speech. Later, software advances allowed Kurzweil software to run on a personal computer as an assistive reading machine for both digital and printed text.



#### Personal computers and the internet (1970s and 1980s)14,15,16

The advent of personal computers in the late 1970s and early '80s, and the introduction of public access to the internet in the late 1980s, created previously unthinkable accessibility opportunities for people with blindness and low vision. The age of computers has generated a whole new set of digital tools and devices that vastly improve access to reading, literacy, and ultimately participation in society by people who are blind and partially-sighted. Most importantly, a wide variety of new accessibility tools designed specifically to run on personal computers, or previously-existing technologies too expensive or too bulky to be widely available to average blind consumers, were suddenly made available easily and at low cost.

https://thatallmayread.ca/explore-history/the-digital-age/game-changing-innovations/ Accessed on 2024-04-11

https://nfb.org/sites/default/files/images/nfb/publications/fr/fr28/fr280109.htm Accessed on 2024-04-11

 $<sup>\</sup>frac{https://www.afb.org/blindness-and-low-vision/using-technology/interviews-technology-pioneers/ray-kurzweil\#:::text=The \%20Kurzweil\%20Reading \%20Machine \%2C\%20Machine \%$ the.text%2Dto%2Dspeech%20synthesizer Accessed on 2024-04-11 https://www.afb.org/aw/5/5/14692#:--text=It%20was%20featured%20on%20all.placed%20in%20schools%20and%20libraries Accessed on 2024-04-11

https://thatallmayread.ca/explore-history/the-digital-age/ Accessed on 2024-04-11 https://www.britannica.com/technology/personal-computer Accessed on 2024-04-11

https://thatallmayread.ca/explore-history/the-digital-age/ Accessed on 2024-04-11



#### DAISY digital book format (1994)<sup>17,18</sup>

DAISY (the Digital Accessible Information System), the international standard for accessible digital talking books, allows audio readers to navigate within a book as print readers do. In 2002, the CNIB Library transitioned its cassette tape audiobook collection to DAISY books on CD. In 2014, the CNIB Library became the Centre for Equitable Library Access (CELA) and hundreds of thousands of books in a variety of accessible formats became available as digital downloads. Today, CELA has more than 1.3 million titles in dozens of languages available in DAISY, synthetic speech, electronic braille, and several other formats, which are able to be accessed anywhere there's an internet connection.



Screen reader software 19,20

JAWS (Job Access With Speech) is a computer screen reader program for Microsoft Windows that allows users who are blind and visually-impaired to read digital text either with text-to-speech output or by refreshable braille display. Jaws for DOS was released in 1989. The Windows version was released in January 1995 and remains one of the leading Windows screen readers.

NonVisual Desktop Access (NVDA) was created in 2006. By 2023, NVDA was the most popular desktop/laptop screen reader in common use and the second most popular primary screen reader throughout the world. Free to download, available in over 40 languages, and with its opensource code allowing its user base to build new features, NVDA is especially popular in developing countries, making it accessible to many people who are blind and visually-impaired who would otherwise not have access to the internet.

Today, with scanning, OCR and braille translation software, screen readers, hundreds of computer-based accessibility tools, the ubiquity of digital-source reading material, and access through the web, people who are blind now have access to nearly all of the same information as sighted people.

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https://daisy.org/about-us/history/ Accessed 2024-04-14

https://thatallmayread.ca/explore-history/the-digital-age/game-changing-innovations-part-2/ Accessed on 2024-04-11 https://makeitfable.com/glossary-term/jaws-job-access-with-speech/ Accessed on 2024-04-11

https://en.wikipedia.org/wiki/NonVisual\_Desktop\_Access Accessed on 2024-04-11



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#### GPS systems/blind navigation (1999)<sup>21</sup>

In the early 2000s, several personal, hand-held GPS systems for people with vision loss came onto the market, allowing users to independently map routes and identify their location and orientation, affording them the first major advance in mobility since the white cane. Dozens of blind navigation apps that run on smartphones have been launched in the past two decades, from Loadstone GPS (2006) to BlindSquare (2015). supporting third-party public transportation apps like Moovit, Uber, Lyft, and many more. These apps allow travellers who have blindness or vision loss to navigate complex urban landscapes with confidence, letting the user mark favourite locations and find out about local restaurants, businesses, and attractions independently.



#### Smartphones (1994/2007)<sup>22,23,24</sup>

First made internet-capable in 1994, these pocket-sized, off-the-shelf computers, which support large print, voice control, and screen

reading, allow users to read and navigate more independently than ever before. Equipped with built-in screen magnifiers and screen readers, smartphones decode paper money, provide text-to-speech voice assistance, take dictation, facilitate texting and braille input and output, and support physical navigation.

With the 2007 launch of the Apple iPhone and its suite of embedded accessibility features, the smartphone became an accessibility tool of choice for users who are blind. Today, there are literally hundreds, if not thousands, of smartphone apps specifically designed for users with vision loss. And the accessibility features on smartphones provide full access to the digital world via the devices' internet capability and GPS locator functions.

Digital convergence and integration with smartphone accessibility tools increasingly gives users who are blind control of household appliances, environmental controls, security systems, and much more, and the next generation of smartphones are expected to include onboard AI, bringing the possibility for even greater accessibility and personal independence that much closer.

In the span of eight decades, technological advancements have fundamentally reshaped the experience of living with blindness, offering unprecedented opportunities for independence and inclusion. As we look to the future, the continued innovation in accessible technology promises even greater empowerment, fostering a world where people living with vision loss can thrive with boundless possibilities.

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<sup>21</sup> https://aerospace.org/article/brief-history-gps Accessed on 2024-04-11

<sup>22</sup> https://simpletexting.com/blog/where-have-we-come-since-the-first-smartphone/#:--text=In%201992%2C%20IBM%20announced%20the,receive%20both%20emails%20and%20 faxes Accessed on 2024-04-11

<sup>23</sup> https://thatallmayread.ca/explore-history/the-digital-age/ Accessed on 2024-04-11

<sup>24 &</sup>lt;a href="https://www.techtarget.com/searchdatacenter/definition/technological-convergence">https://www.techtarget.com/searchdatacenter/definition/technological-convergence</a> Accessed on 2023-04-27

# CNIB Acts as a Catalyst for Change with New Strategic Plan to Create a More Inclusive Canada

n a world full of opportunity, CNIB has a bold mission: to change social attitudes and unlock the unseen potential of people impacted by blindness. The non-profit envisions a future where every Canadian, regardless of whether they're sighted or blind, can live the lives they choose.

This mission is at the heart of CNIB's 2023–2028 strategic plan, The Way Forward, which serves as a rally cry for an inclusive world where people who are blind, Deafblind, or who have low vision are not only integrated, but also celebrated members of society with equal opportunities.

"This isn't just a strategic plan," says Angela Bonfanti, COO of CNIB. "It's a commitment to reshaping the landscape of opportunities for Canadians impacted by blindness, ensuring every individual can live life on their own terms."

Built on the direction and feedback of people with sight loss and their supporters across Canada, the plan puts a magnifying glass on the societal constraints facing Canadians who are blind and outlines three commitments to help address these barriers:

#### Attitude Is Everything

CNIB is committed to increasing understanding of blindness to dispel misconceptions about people who are blind, Deafblind, or who have low vision so the rest of the world can believe in what they can do.

#### Safe and Accessible Journeys

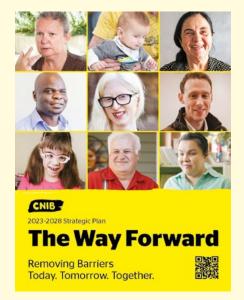
CNIB is committed to developing accessible transit options that make travel safer so people with sight loss can get where they need to go, confidently and independently.

#### **Our Kids Will Thrive**

CNIB is committed to influencing change within the education and health care community and enhancing supports so that children who are blind have the same opportunities as their sighted peers. This commitment includes the creation of The Charter of Rights of Children Who Are Blind Deafblind, or Low Vision in Canada, which CNIB launched in November 2023.

Already, CNIB has taken powerful action to meet these commitments. Since the launch of The Way Forward, the organization has delivered two campaigns designed to uncover and address barriers to travel, with its "Get on Board" campaign targeting transit accessibility and its "SnoWay" campaign, which put barriers caused by improper snow removal under the spotlight.

CNIB has also committed to working closely with media outlets to improve representation of and for people who are blind, and the organization's soonto-be-launched CNIB Next Generation program promises to improve services for children and families impacted by blindness to ensure they have the wraparound support they need to thrive.





Left, Angela Bonfanti, CNIB Chief Operating Officer, and right, Robert Fenton, Board Chair of CNIB, with his guide dog. Angela and Bob posing at CNIB's launch of its Moving Forward Strategic Plan

PHOTO CREDIT: CNIB PHOTO LIBRARY

"Every person who is blind, Deafblind, or who has low vision should have the same opportunities to dream and succeed as anyone else," says Robert Fenton, Chair of CNIB's Board of Directors. "The Way Forward brings us one step closer to making that goal a reality. We're not asking anymore, we're demanding it."

To learn more about The Way Forward, visit <a href="mailto:cnib.ca/wayforward">cnib.ca/wayforward</a>.



The 1944 Legacy Society is an esteemed group of likeminded individuals who encourage members to include the Canadian Council of the Blind in their wills. By doing so, 1944 Legacy Society members are honouring their commitment to a better future for all Canadians, Members are recognized on a Digital Donor Wall and receive an exclusive pin.

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while offering you the opportunity to empower the blind community. Your legacy can live on through technology training, preventive eye health advocacy, and innovative research.

Including a gift in your will can take various forms, such as a percentage of your estate or property, a fixed amount, or stocks and other investments. Consult a legal professional to create a lasting legacy for the blind, and to ensure your will is binding, accurate, and optimized for tax benefits.



#### Canadian Council of the Blind

#### **LOCAL CCB CHAPTERS**

CANADIAN COUNCIL OF THE BLIND



LE CONSEIL CANADIEN DES AVEUGLES

#### **BC-YUKON DIVISION**

100 Mile House & District Chapter Alberni Valley Chapter **BC All Abilities Chapter Bowen Island Chapter** Campbell River Chapter Chilliwack & District Chapter Comox Valley Chapter **Dogwood Chapter** Festival of Friends Chapter GTT BC Chapter Kamloops White Cane Chapter Kelowna Blind Curlers Chapter Kelowna Chapter **Knotty Knitters & Crazy** Crocheters Chapter **Lower Mainland Chapter** Nanaimo Chapter Parksville & District 69 Chapter Powell River Chapter Prince George Blind **Curling Chapter** Provincial Book Club Chapter South Okanagan Chapter Sunshine Coast White Cane Chapter

#### **ALBERTA DIVISION**

**Lovers Chapter** 

Vancouver Arts & Culture

Calgary Club Chapter Edmonton Cribbage Chapter GTT Edmonton Chapter

## SASKATCHEWAN DIVISION

Regina Chapter

**ONTARIO DIVISION** Afloat Chapter Carleton University Chapter Chatham-Kent Chapter Club '60' Barrie Chapter Cornwall Chapter **Dragon Boat Toronto** Chapter GTT North Bay Chapter **Hamilton Blind Curlers** Chapter **Hamilton Chapter** Hamilton Juniors Chapter Hands of Fire Chapter Kingston Friendship Chapter Listeners Book Club **London Chapter London Vision Impaired Curlers Chapter** McMaster University Chapter Mississauga V.I.P. Chapter Ontario Blind Golf Chapter Ottawa Blind Curlers Club Ottawa Chapter Ottawa University Chapter Pembroke White Cane Chapter Peterborough Chapter

Roadrunners Chapter

Sault Ste. Marie White

Thunder Bay & District

**Rocks Chapter** 

Cane Chapter

Chapter

Toronto Blind Curling Club
Toronto Ski Hawks
Ski Club Chapter
Toronto Visionaries Chapter
Waterloo Regional Club
Windsor/Essex Low Vision
Social & Support Chapter
York Region Lighthouse
Chapter

## PRINCE EDWARD ISLAND DIVISION

Prince County Chapter Queensland Chapter Summerside Socialites Chapter

## NEW BRUNSWICK DIVISION

Bathurst Club Miramichi Club Moncton Club

#### **NOVA SCOTIA DIVISION**

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

# NEWFOUNDLAND AND LABRADOR DIVISION

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

#### **NATIONAL CHAPTERS**

Blind Golf Canada Chapter

# CANADIAN COUNCIL OF THE BLIND NATIONAL BOARD OF DIRECTORS

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

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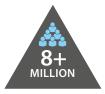




Canadians who say good vision health is critical/important to overall health



Canadians living with vision loss



Canadians at risk of eye threatening conditions



Annual cost of vision loss

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

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

#### **OUR KEY GOALS FOR BILL C-284**



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



Increasing investments for made-in-Canada research



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



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



Investments for eye health awareness, advocacy and support groups

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













FIGHTING VAINO BLINDNESS LA CÉ CANADA CANA















#### We Wouldn't Be Where We Are Without You



#### Your Support Is Helping Us Change What It Means to Be Blind

The Canadian Council of the Blind (CCB) wishes to express its gratitude to all our sponsors, partners, stakeholders, and friends for their generous contributions and impactful support of the community of people living with vision loss.

Your continued presence is critical if the CCB is to continue to grow and develop, to use its powerful voice not only in addressing vision loss but in speaking out on behalf of vision health, and to engage in the conversation about how blindness and vision loss are preventable. Therefore, it's important that we demonstrate to you, as a group, our gratitude and appreciation for your confidence in and support of the Council.

The work of the CCB is having a positive impact on the vision loss and vision health communities. Together we are a powerful voice, and we wouldn't be where were at without you. Together we are making a difference. Together we are working to change what it means to be blind. That's important. Thank you!

#### PARTICIPATING EVENT GOLD SPONSORS















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#### PARTNERS AND STAKEHOLDERS



























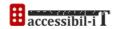








#### FRIENDS AND SUPPLIERS



























THANK YOU

# Stay alert: recognizing signs and symptoms of Geographic Atrophy

**Geographic Atrophy (GA)** is an advanced form of dry age-related macular degeneration (AMD) which can lead to **permanent vision loss**.

### Some early symptoms of GA include:



Difficulty seeing in or adjusting to the dark



Straight lines appearing crooked



A growing blurry spot in the centre of vision

# Living With GA

Visit www.LivingWithGA.ca for helpful resources designed for patients with GA and their caregivers

Scan the QR code with your phone's camera to visit www.LivingWithGA.ca



GA=geographic atrophy.

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# Shaping the future of vision.

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

www.rochecanada.com

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

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