

CCB's Virtual Expo Forum
 Topic: Ontario's Assistive Devices Program
 Sat., Feb. 13 at 2 p.m.
 Register here: bit.ly/36mQZds

FBC's View Point
 Topic: Uncovering the Role of Vitamin D in AMD
 Wed., Feb. 17 at 10:30 a.m.
 Register here: bit.ly/3r2r96f

CCB's Vision 2021 Virtual Summit
 Topic: The Impact of the COVID-19 Pandemic
 Wed., Feb. 17 at 2 p.m.
 Register here: bit.ly/3r3EviW

CCB's Vision 2021 Virtual Gala
 White Cane Week's Annual Award Event
 Thurs., Feb. 18 at 2 p.m.
 Register here: bit.ly/3j1JHky

i For more information and to register, visit ccbnational.net and fightingblindness.ca/events/virtual-events.

Living with Vision Loss

It's White Cane Week

The Canadian Council of the Blind (CCB) is the Voice of the Blind in Canada™ and was founded 77 years ago in 1944 by blind veterans who were returning from the war and by schools of the blind. The CCB is a membership-based registered charity with 84 local chapters nationally that bring together Canadians who are blind, deaf-blind, or partially-sighted to share

common interests and social activities. Its main goal is to promote a sense of purpose and self-esteem along with an enhanced quality of life amongst its members. The CCB is unwavering in working toward improved accessibility and a barrier-free Canada.

Each year during the first full week of February the CCB celebrates White Cane Week. Scheduled from Feb. 7 to 13, the year 2021 will mark its 18th annual event. This year,

the CCB has gone virtual in an attempt to fill the gap that has been created where social interactions and gatherings aren't possible. In celebrating White Cane Week, the CCB aims to bring public awareness and appreciation to issues of accessibility, health, and inclusion.

The CCB works collaboratively with key government agencies and stakeholder coalitions including several national organizations. It's through these relationships

and efforts that the CCB is able to promote a better understanding of the barriers faced by those living with vision loss.

The CCB is proud of these efforts to change what it means to be blind and of its leadership role in the vision loss community. Through its collaborations and independent work, it has played a key role in attaining relevant legislation, services, and appropriate eye disease treatments. **👁**

Dear reader,

We at the Canadian Council of the Blind (CCB), Fighting Blindness Canada, and the International Federation on Ageing ask for your support on behalf of the over 1.5 million Canadians who are blind, deaf-blind, and partially-sighted and who are experiencing special challenges due to the COVID-19 pandemic. We believe that people living with vision loss should be given a priority position, close behind our heroic first responders and vulnerable seniors, to be vaccinated against COVID-19. People living with vision loss are members of a vulnerable community and have been living with economic, social, and emotional stress since even before this pandemic.

The CCB recently conducted a survey asking those living with vision loss to report the effect of the pandemic on their daily lives. The survey's results were summarized in the report *The Impact of the COVID-19 Pandemic on Canadians Who Are Blind, Deaf-Blind, and Partially-Sighted*.

The results of the survey's 572 respondents revealed the existence of high levels of stress, anxiety, fear, and even depression. When asked to describe the pandemic's impact on their lives, one respondent expressed the difficulties they were experiencing as follows:

"What is affecting my mental health is this prolonged and extreme isolation. As a blind person I already live a fairly limited life when referring to freedom of movement and independence and now even that small wedge of my active life has been completely eradicated."

We request your help in relieving the burdens and stress resulting from the impact of the COVID-19 pandemic on people with vision loss. We ask the government to review their situation and to strategize on how this community can be given priority access to the vaccine. Timely action is essential.

Yours sincerely,



Dr. Jane Barratt
 Secretary General,
 International
 Federation on
 Ageing

J. Barratt



Doug Earle
 President & CEO,
 Fighting Blindness
 Canada

D. Earle



Louise Gillis
 President,
 Canadian Council
 of the Blind

Louise Gillis



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Welcome to the future of medicine

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In the Midst of the Pandemic, Vision Health Policy Is Evolving

D.F. McCourt

Canadians have been avoiding non-essential outings, as they should, but it hasn't always been clear what that means for our health-related appointments for non-COVID-19 concerns like vision health.

"During this pandemic, we're all being told to keep healthy, stay safe, and protect ourselves and our loved ones," says Dr. Jane Barratt, Secretary General of the International Federation on Ageing (IFA). "Part of that, particularly if we have an eye condition, is keeping up with our routine screening as much as is possible in this environment."

For vision especially, it doesn't make sense to put off assessment or treatment if you think your eyesight may be at risk. "The critical thing is that people who have age-related macular degeneration or diabetic eye disease know that their treatment is time-sensitive," says Dr. Barratt. "The IFA has every confidence in the safety measures that ophthalmologists have in place and regularly review."

Treatment options expanding as policy adapts

Though it has sometimes felt like the world's standing still over the last year, medical research and policy remain fast-moving. The advent of biologic therapies revolutionized treatment for retinal diseases, but now with biosimilars — which are versions of the originator treatment — entering the market in Canada, conversations about patient choice, safety, and effectiveness must be at the forefront of policy and good practice.

"Retina specialists have been using biologics since 2006 in Canada, so we have 15 years of experience with three different biologics," says Calgary-based retina specialist Dr. Geoff Williams. "This has provided a good sense of how well they work and how safe they are. Biosimilars, on the other hand, are very new, so it's going to take some time for doctors to get experience with them and feel comfortable."

Similar, but not identical

Biosimilars are required to demonstrate similar efficacy to

originator biologics, but they aren't chemically identical. Being newer on the scene, biosimilars have less data available, and most doctors still have very little, if any, experience with them.

One of the big concerns centres around government policy, which will vary between provinces, particularly as it relates to forced switching to biosimilars for patients who are already on an originator biologic treatment. "Biosimilar policy is going to have a direct impact on patients," says Dr. Williams. "If something is working well for a patient, they generally don't want to see their treatment change. We've seen this pushback already in Alberta with switching to rheumatological biosimilars, with some patients feeling that the biosimilar wasn't working as well for them."

The right to decide

More options for treatment are always welcome, but experts want to ensure that having new choices actually results in patients having more choice. "It's like the COVID-19 vaccine," says Dr. Barratt. "With five different authorized



Dr. Jane Barratt
Secretary General,
International
Federation on
Ageing



Dr. Geoff Williams
Director &
Co-Founder,
Calgary Retina
Consultants

vaccines becoming available, I know they're all safe and effective, but I'm still going to want to know which one goes in my arm, and why it was chosen over the others." The IFA has several resources for patients and the vision community which can be accessed by visiting its website.

As we remind ourselves to make vision a health priority in the midst of the pandemic, it's important that we inform ourselves about the therapies available and ensure that all voices are being heard in decisions related to treatment choice.

i Biosimilar policy for retinal disease is still being developed. Make your voice heard. Learn more at eyeseeyou.care.

This article was made possible with support from a research-based pharmaceutical company.

Research Makes Great Strides in Solving a Stem Cell Mystery

Fay Knights and Dr. Larissa Moniz

Fighting Blindness Canada (FBC), the largest private funder of vision research in Canada, has invested over \$40 million in the most promising vision research to understand the causes of vision loss and advance new treatments and cures for blinding eye diseases. This investment means that there are now treatments to prevent vision loss for people living with glaucoma, age-related macular degeneration, and diabetes-related vision loss, and that as of 2020, the first sight-restoring gene therapy treatment for an inherited retinal disease is now available in Canada.

In the last year, FBC has funded 26 grants, including six new outstanding research projects that represent some of

the most ambitious and impactful vision science initiatives in Canada. One of the grants is to support research by Dr. Michel Cayouette and his team at the Montreal Clinical Research Institute, who identified two molecules that drive stem cells to make cone photoreceptor cells, the light-sensing cells responsible for detail and central vision that are lost in eye diseases like retinitis pigmentosa and Stargardt disease.

Stem cells have the ability to make many new types of cells and are being considered as treatments for blinding eye diseases to replace cells that have been lost or damaged.

Innovating for a brighter future

A large challenge is figuring out

how to encourage stem cells to make the specific type of retinal cell needed for treatment — in this case cone photoreceptors — instead of another type of retinal cell.

Dr. Cayouette's research sheds light on this process, showing that two genes are turned on when stem cells are making cone cells and turned off when they aren't. The results of Dr. Cayouette's research also show that artificially turning on the genes drives stem cells to make more cone cells.

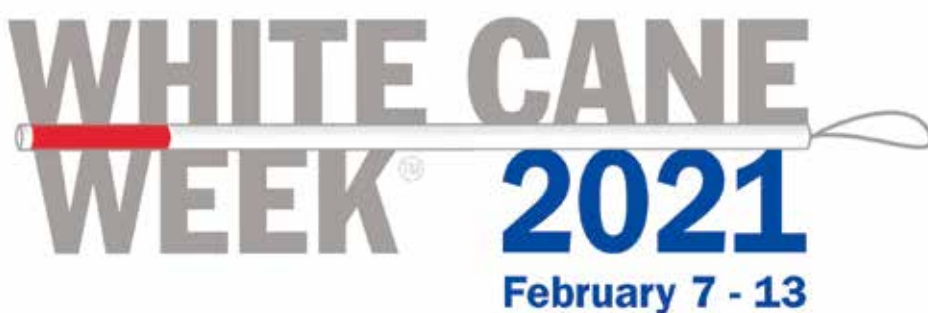
"The identification of these genes is exciting because it marks an important step toward understanding how exactly cone cells are generated, which is providing new therapeutic opportunities to replace cone cells lost in various retinal dys-

trophies," says Dr. Cayouette. He and his team are now studying whether this information can be used in regenerative medicine.

This impressive discovery is giving scientists the information and inspiration they need as they develop stem cell therapies, moving scientists closer to being able to develop an effective stem cell therapy for retinal diseases.

FBC is proud to fund innovative and promising vision research like the work of Dr. Cayouette and his team, helping to create a brighter future for the 1.5 million Canadians living with vision loss and blindness.

i Learn more about FBC's mission to fund sight-saving research at fightingblindness.ca.



White Cane Week Vision 2021 Gold Partners:



Preventable Vision Loss Due to the Pandemic

Dr. Keith D. Gordon

The COVID-19 pandemic has brutally exposed those living with vision impairment to even greater stress than the sighted community due to social distancing requirements, impacting their ability to negotiate the outdoors and public spaces. Many of those who need assistance are no longer able to leave their homes, leading to greater solitude, depression, and the potential for further sight loss.

Adequate treatment requires regular care

Two of the major causes of vision loss among older adults, wet age-related macular degeneration (wAMD) and diabetic macular edema (DME), require regular injections into the eye to prevent further vision deterioration. In spite of the dire consequences that may be experienced due to patients missing their injections, clinicians are reporting that up to one third of patients are missing their injection visits.

In April 2020, the Canadian Council of the Blind (CCB) conducted a survey of people living with vision loss across Canada in order to better understand the impact of COVID-19 on their lives. Many respondents



Clinicians are reporting that up to one third of patients are missing their injection visits.

said they were concerned that they might lose vision as a result of not being able to see their eye doctor. One respondent commented: “I need injections every four weeks in order to maintain my current visual acuity. If I get sick and am unable to see my doctor... I am afraid my vision will deteriorate. His work of doing injections for [wAMD] is an essential service for me and for many others.”

What’s more, control of vision loss due to wAMD, DME, or glaucoma relies on early diagnosis and treatment of the disease. Early diagnosis is achieved through a complete eye examination by an optometrist or ophthalmologist. It’s therefore particularly concerning that optometrists report that up to 50 percent of their patients missed

regular appointments due to the pandemic. This means that many patients will have irreversibly lost vision by the time their disease is diagnosed and treated.

Access in the time of COVID-19

At the same time, both ophthalmologists and optometrists fear that they may become swamped once the pandemic is over and the backlog of patients clamours to receive their eye injections or eye examinations.

A study conducted by the Canadian Medical Association shows a significant decrease in the number of cataract surgeries performed during the pandemic and a corresponding increase in the wait times for surgery. This means that people needing cataract surgery will unnecessarily lose vision while they wait for surgery and may be at risk of some of the deleterious effects of vision loss, such as falls and clinical depression.

To safely bring patients with eye diseases back to the clinic to receive their scheduled sight-saving care, prevent avoidable blindness, and reduce the asso-

ciated negative impact on those affected, the CCB, together with other members of Retina Action, a global coalition of organizations concerned with vision loss, is calling on governments in Canada and around the world to develop plans that provide additional support for the provision of eye care at this time. Such plans should include additional funding for eye examinations; eye injections or medications for the treatment of wAMD, DME, and glaucoma; and additional cataract surgeries. Furthermore, it’s essential that people living with vision loss be given priority with respect to COVID-19 vaccination to enable them to return to regular eye doctor visits and treatments, and to minimize the isolation and loneliness that those with vision loss are currently experiencing.



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



Julie Martin sits in a chair with her iPad in hand.
Photo courtesy of AMI.

Partially-Sighted Reporter Speaks from the Heart to the Community

Anne Pappmehl

Every day is an opportunity to educate people,” says Julie Martin, a community reporter with Accessible Media Inc. (AMI), a not-for-profit media company serving the blind and partially-sighted community. An unconventional opportunity to do that presented itself recently when a bout of pleurisy landed Martin in the ER minutes before her scheduled weekly broadcast on AMI-audio’s *Kelly and Company*. “They were about to do a chest X-ray and I asked the doctor if they could postpone it for 15 minutes until after I filed my report,” says Martin. The doctor and nurse listened in another room, afterwards expressing awe at the program and how they planned to tell their partially-sighted family members about AMI.

Discovering AMI helped rebuild confidence and self-worth

Martin, 59, a resident of Pictou County, NS, is partially-sighted herself. Born with retinitis pigmentosa, a progressive disease that causes gradual disintegration of the retina, Martin at first chose to ignore her condition — until age 31, when doctors told her she was legally blind. She struggled with isolation, self-worth, and daily living challenges for years until 2012, when she discovered AMI while visiting friends. “I thought it was just brilliant,” she says.

Martin began tuning in to AMI-tv and AMI-audio regularly, soon after becoming a member of the AMI research panel and offering feedback, which was incorporated into the company’s programming. “The more I watched AMI-tv, the

more confidence it gave me, and it made me realize that I wasn’t the only one who felt like this or has struggled with certain challenges,” she says.

Now, as an AMI-audio community reporter, she’s hearing other people’s stories and listening to reports from across Canada. “I’m taking what they’re saying and using that to improve my life,” says Martin. “It also gives me the ability to educate the sighted community, who are trying so hard to ensure accessibility and inclusion of the disability community.”

COVID-19 exacerbates daily living and isolation challenges

For people who navigate the world by feel, the need to physically distance and avoid touching things due to the COVID-19 pandemic makes independent living that much harder. “As a

result, many visually-impaired people rely on others for shopping and errands and stay at home more, which adds to their isolation,” says Martin.

AMI’s inclusive and accessible programming helps keep Canadians connected. Martin’s advice to others in the blind and partially-sighted community? “Just check it out. There’s so much you’re missing out on if you don’t know it’s there — from new technologies like adaptive tips for your cane to how to set up inclusive programs in the community.”



Learn more about how AMI’s inclusive content is enriching the lives of the blind and partially-sighted community and helping them feel connected — especially during the COVID-19 pandemic — by visiting ami.ca.

This article was sponsored by AMI.

