

THE CANADIAN COUNCIL OF THE BLIND

WHITE CANE MAGAZINE 2021

White Cane

The Voice of the Blind in Canada™

Magazine



LET'S BEAT COVID-19

- WEAR A MASK •
- KEEP SOCIAL DISTANCING •
- WASH YOUR HANDS - OFTEN •
- SHELTER IN PLACE •
- GET VACCINATED ASAP •



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Shelter in Place



Get Vaccinated ASAP



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WHITE CANE WEEK 2021

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CANADIAN COUNCIL OF THE BLIND



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2020 Overview



This year was a year to remember, but certainly not in the way the Canadian Council of the Blind (CCB) planned! We had looked at 2020 as a year to educate, advocate, and have new treatments toward 20/20 eye sight. We called it The Year of Vision 2020.

The year started off strong. Our White Cane Week in February was a resounding success. The week spanned 10 days with a forum with panellists, a curling competition, various local chapter initiatives, the Experience Expo, the Vision 2020 Gala Dinner, and the Canadian Vision 2020 Summit. We had a great deal of media coverage stressing 20/20 vision by encouraging eye examinations for all ages and sharing information about the potential of exciting new treatments for some eye diseases.

March is when we saw the whole world change due to the COVID-19 pandemic. All domestic and international travel gradually came to a halt and lockdowns began. The first wave of COVID-19 arriving in Canada resulted in many challenges for all of us in the visually-impaired community, including concerns about accessing health

care services, buying groceries and completing everyday tasks, personal and community safety, social isolation and loneliness, meeting financial responsibilities, and more.

In response, the CCB undertook a survey regarding the impact of the COVID-19 pandemic on people with sight loss. The report on this survey, *The Impact of the COVID-19 Pandemic on Canadians Who Are Blind, Deaf-Blind, and Partially-Sighted*, was released in April. Many fears were recognized and reported to the public and, most importantly, to the government.

During this time, the CCB continued to present our Get Together with Technology (GTT) programming, and the power of peer mentoring helped keep our GTT members connected and supported. Our staff also increased the number of calls across Canada to all persons with sight loss, enabling them to stay in touch with friends and relatives and to learn new ways of using technology.

Now that we're in the second wave of the COVID-19 pandemic, we can clearly see the burdens it has placed on everybody's life. Throughout the pandemic, we at the CCB continued with our work to improve the quality of life for those living with sight loss through the patient submissions submitted to the Canadian Agency for Drugs and Technologies in Health (CADTH) along with partnerships with other organizations of and for the blind. This has resulted in new drugs for age-related macular degeneration, glaucoma, and one form of retinitis pigmentosa. We continue to work with the provinces to get their approval for coverage for these treatments.

In our relationship with Best Medicines Coalition, there's a continuance of improving treatments for other disease processes that may also affect persons living with sight loss. We've also been active in the Biosimilars Working Group, as we begin to see these drugs used in not only arthritis, gastrointestinal disorders, and cancer but also in eye care.

The Canadian Transportation Agency (CTA) is also a very important organization for all of us who rely on air, rail, or ferry services. With the new COVID-19 regulations, the CCB and several other organizations of or for persons with disabilities have been busy working to ensure that we get the best possible conditions in place for travel.

A government agency that we're currently working with, Canadian Radio-television and Telecommunications (CRTC), made it possible to receive prime time described video on most programs. Due to the fact that many of us have been at home more, we rely on radio and TV much more. We're so grateful that Accessible Media Inc. (AMI) has supplied us with a great network of programming to view and listen to on TV and radio, not only through the English network but also through its French channel.

This year, the CCB has also been involved with the International Federation on Ageing through webinars that Keith Gordon, Jim Tokos, and I have participated in by giving presentations regarding the coronavirus and the use of biosimilars in eye diseases. The CCB also gave presentations at the Alliance for Equality of Blind Canadians (AEB) Conference this fall.

We have had a strong partnership with Fighting Blindness Canada (FBC) throughout the year, jointly working on drug submissions, the White Cane Week forum, the Vision 2020 Gala Dinner, and the Canadian Vision 2020 Summit, among

EIGHTEENTH ANNUAL WHITE CANE WEEK™

other initiatives. Thank you to FBC President and CEO Doug Earle and staff for all your great work and for bringing hope to the vision loss community.

CCB Vice President Jim Tokos and I have been very active with the World Blind Union (WBU) as two of the Canadian delegates. The General Assembly was not able to be held in person in 2020, so now we're looking forward to the virtual event this spring. The WBU continues to do great work. It's important to note the work of Charles Mossop and other North American delegates in their efforts to bring several Caribbean countries into the WBU as full members.

The CCB Board of Directors and committees have been very active on advocacy concerns and membership initiatives throughout the year. Thank you to all who have been involved in this very important work. Through the Bylaws Committee, the CCB has come up with bylaws that will be voted on in February 2021.

The CCB Board was disappointed that we've had to put off the 2021 AMI Curling Championship until 2022. Many other sporting activities have also been cancelled or postponed to 2022. We look forward to being able to start up these activities later in 2021.

Many of our White Cane Week events this year will be happen online, including the Expo Vision 2021 Forum, the Vision 2021 Summit, and the Vision 2021 Gala.

As the year comes to a close, we're hoping that all stay safe and we look forward to a better year ahead. All of our staff have been working from home most of the time and our Board of Directors is holding all meetings by phone. I'd like to thank each and every person who has supported our organization over the past year during difficult situations. It's through support and hard work that the CCB has been able to continue with our programs for Canadians with sight loss.

As many of you already know, the CCB's election will take place in May 2021. I will not be reoffering as President but will be in the role of Past President, and will remain active as a support for the new Board of Directors. The past 10+ years have been very interesting and rewarding. Throughout this time, I've worked with many people who have become great friends. We've accomplished a great deal, particularly in the last few years, and the CCB has become better known throughout Canada as well as internationally. I'm grateful for the time I've spent as the CCB's National President, and look forward to welcoming our new President this spring.

We all look forward to a healthy and prosperous New Year. Take care and stay safe.

Sincerely,



Louise Gillis, National President, CCB



Due to COVID-19 restrictions, it was necessary to cancel our **2021 AMI Canadian Vision Impaired Curling Championship**. We look forward to its return in 2022.

TEAM ALBERTA – 2020 CHAMPS



Shown here with Peter Burke, AMI VP of Marketing and Communications (far right), is Team Alberta, winners of the 2020 AMI Canadian Vision Impaired Curling Championship.

FROM LEFT TO RIGHT:

Jim Hayden
Dave Erno
Natalie Morin (Skip)
Lori Hysert
Mandy Collins
Bruce MacDonald
Peter Burke (AMI)

PHOTO: Andre Martin

Today's Canadian Council of the Blind

CURLING PHOTO: Andre Martin



The Canadian Council of the Blind (CCB) is the Voice of the Blind in Canada™. It was founded in 1944 by blind veterans returning from the war and 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 works tirelessly for people with vision loss through its advocacy, awareness campaigns, peer mentoring, sports adapted for people with vision loss, and the promotion of health and fitness. The CCB encourages peer support, as with its national Get Together with Technology (GTT) program, and provides programs and initiatives for the conservation of sight and the prevention of vision loss for all. These include the CCB's Mobile Eye Clinics (MECs) and public awareness campaigns for vision health through regular eye exams. The CCB Youth Engagement program offers youth aged 18 to 30 a safe platform and an opportunity to engage in discussion with their peers and to build leadership skills.

The CCB promotes public awareness through *White Cane Magazine*, its monthly newsletter, its social media channels, and its annual White Cane Week. White Cane Week events such as the AMI Canadian Vision Impaired Curling Championship, the Experience Expo, the Expo Forum, the Vision 2021 Virtual Gala, and the Vision 2021 Virtual Summits (scheduled for February and May in 2021) generate solid audiences from stakeholders and

the blind, deaf-blind, and partially-sighted community.

In 2019, the CCB started to become more actively involved in research in order to better advocate for the needs of people living with vision loss and to support its initiatives related to the conservation of sight and the prevention of vision loss. Since that time, the CCB has conducted two research studies related to accessible devices and a study on the impact of the COVID-19 pandemic on people living with vision loss, and is currently directing a study on the prevalence and cost of vision loss in Canada. A number of research collaborations with university researchers and other stakeholders on a wide range of issues that affect people living with vision loss are also under development.

The CCB works collaboratively with key government agencies and stakeholder coalitions including several national organizations of and for the blind, health care organizations, various accessibility committees, and international organizations all dedicated to building public awareness and improving the well-being and quality of life of people with seeing disabilities. 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. □



The Pandemic Sheds Light on Ingenuity but Also Challenges

I think we can all agree that 2020 has been a year that's destined for the history books. It was one of the most unique years the majority of us will ever know. As it had been over 100 years since our collective society had weathered a global pandemic, it came as a huge surprise to us all.

The learning curve was steeper for some of us than others. Those of us in marginalized communities had to quickly adapt to an ever-changing landscape filled with new rules and guidelines — guidelines that included everything from how close we could stand to someone else to whom we could visit.

It began to feel like every day brought new information or advice on what to do and what not to do. Things became very confusing, very quickly, for everyone.

This was especially challenging for those of us in the visually-impaired community. I heard from lots of friends who consider themselves fiercely independent, who stopped going out, stopped seeing friends and family, and had to rely on others for more help than they were accustomed to.

These measures were taken in order to keep themselves, and others, healthy and safe.

Nonetheless, we were rapidly thrown into a world that now included directional markers on the floors of stores, plexiglass barriers, and anxious individuals who had the potential to get quite upset if you accidentally entered their six-foot personal boundary.

These new protocols became obstacles for those of us with visual disabilities. Now, before venturing out for basic services such as groceries, one had to consider how to successfully navigate these new visual cues as well as all the sensitivities surrounding them. And given the rate at which these new rules were implemented, it's almost as though the requirements for people with disabilities were pushed aside and forgotten.

I would be lying if I said it wasn't difficult — it was extremely difficult — but typical of our community, we rose to the challenge.

Within days of the beginning of the lockdown in March, the Canadian Council of the Blind (CCB)'s Get Together with Technology program moved all of its programming online and began training members on how to use technology to stay in touch with friends and family. Training others on how to shop online allowed people to get what they needed independently again. We also immediately reached out to isolated members of the community and made sure they were OK and that they had what they needed.

We leveraged available technology such as the popular Zoom video conferencing tool and used it to our full advantage. Innovative approaches to training and peer support were deployed through CCB's resources, putting people in touch with each other once more.

People who had never used a smartphone before began talking to friends and family all across the country, face to face again, albeit virtually. This was so important to maintaining the social contact that was suddenly severely lacking amongst us.

We jumped to action and advocated for support from the federal government for people with disabilities, which came as financial assistance in October. This helped to offset some of the costs incurred by members of the disabled community related to the pandemic.

These are just a few examples of how adaptive, creative, and resilient the visually-impaired community is. Unfortunately, barriers are not new to us. Most of us live with them every day in some form or another. What defines us is how we overcome them.

This pandemic has been one of the greatest challenges to our community, but we faced it, and continue to face it, head on, determined to rise above it and to make our way through to the other side.

We support each other when we need it most, and that really makes me proud to be part of this community.

Although White Cane Week will be different this year, the spirit of the event remains the same. Please join me this year in continuing to support our peers, showcase our abilities, and trust in ourselves that we know we can overcome any challenge put in our way.

A handwritten signature in black ink that reads "Mike Potvin". The signature is fluid and cursive.

Mike Potvin, Editor, *White Cane Magazine* 2021

Will old age stop us from seeing our grandkids?

80% of visually impaired
people are over the
age of 50

80% of all visual impairment
can be prevented
or cured

THE CANADIAN COUNCIL OF THE BLIND PRESENTS

GERRY CHEVALIER

WITH THE 2021 PERSON OF THE YEAR AWARD

BY MIKE POTVIN

The Canadian Council of the Blind (CCB) is extremely pleased to name Gerry Chevalier as this year's White Cane Week Person of the Year.

Gerry is an ardent supporter of the blind community, with a particular passion for assistive technology.

"Harnessing the power of technology greatly levels the playing field for people with visual disabilities," says Gerry. "I'm a strong advocate for access to assistive technology both in mainstream technologies and specialized devices, because it can increase a person's independence by allowing them to participate more fully in school, work, and the community."

But as the popular saying goes, technology is only as good as its user, which is certainly true for assistive technology.

"Training on the technology is a key component of the equation," says Gerry. "It's so important that people build and maintain their tech skills so they can capitalize on all of technology's potential. This motivates me to pay forward the skills I've learned and the help I've gained from others along my journey."

And Gerry is the kind of person to put his money where his mouth is. Since starting the Get Together with Technology (GTT) group in Edmonton, he has been an instrumental member of the team, introducing innovative communication and training initiatives such as a weekly blog and podcasts.

"Gerry exemplifies leadership, especially in the realm of peer support and mentoring," says Louise Gillis, CCB National President. "He excels in helping others and is a loyal supporter of our organization and our members."

Gerry is a graduate of the University of Alberta with a Bachelor of Science, specializing in Computing Science. He was an entrepreneur and software developer of small business accounting systems for over 25 years. Over the course of his career, Gerry became blind due to retinitis pigmentosa (RP). He has used Windows primarily with JAWS for over 20 years. In 2004, Gerry joined HumanWare as the Product Manager for its popular Victor Reader line of DAISY digital talking book players.

Now retired, Gerry volunteers as the co-coordinator of GTT Edmonton, which is a chapter of the CCB. GTT Edmonton is a self-help peer mentoring group of blind and visually-impaired people who meet monthly to share their



experiences and learn how assistive technologies can help them lead more independent lives.

When asked what his most important message is regarding technology and vision impairment, Gerry shares an important message for all ages: "For the parents of young with severe vision challenges, ensure that your child learns braille. Too many parents think braille is old-fashioned in the digital age, but it's exactly the opposite. Braille is more pervasive than ever because of technology and remains the only way for children to gain the literacy skills they need to succeed later in life. For the older folks who suffer from age-related vision impairment, get help to learn the many technology aids that can help you maintain your independence in your senior years. It's not just computers anymore. There are many aids that can assist you."

Gerry's passion for helping others is evident. At GTT, he's always willing to lend a helping hand and to share his extensive technological knowledge. With his strong sense of community-building, altruism, and team spirit, Gerry is wholly deserving of being named the CCB's 2021 Person of the Year. □

CCB 2021 PRESIDENT'S AWARD RECIPIENT

DOUG EARLE and the Team at Fighting Blindness Canada

This year we mark the bestowal of the 10th Annual President's Award, which is given annually to an individual, organization, or entity that in their work or service with or for the blind, deaf-blind, and partially-sighted has made a real difference in improving the quality of life of the members of this community. The President's Award recognizes leadership expressed in one's field, important contributions, commitment, and advancement of opportunity. These are all attributes and accomplishments that a recipient exudes and which serve to showcase acceptance, understanding, and a clear recognition that people living with vision loss are equal and contributing members of Canadian society.



This year's President's Award recipients are Doug Earle and the team at Fighting Blindness Canada (FBC). In bestowing the award, Canadian Council of the Blind (CCB) President Louise Gillis stated, "I can think of no more appropriate, fitting, deserving, and prestigious charitable organization or stakeholder partner than FBC. Our friends at FBC are leading the way in funding research into vi-

sion loss eye diseases, driven by the leadership of Doug Earle."

Doug Earle was appointed President and CEO of FBC in December of 2018. He has led the organization through the launch of a new strategic plan to fund vision research into all blinding eye diseases, which led the organization to change its name from the Foundation Fighting Blindness to Fighting Blindness Canada in April of 2019.

Right from the beginning, Doug outreached to the vision loss community to build bridges and enhance partnerships to support advocacy on behalf of the vision loss community. He was instrumental in the co-hosting partnership with the CCB of the Canada Vision 2020 Summit in February of 2020. The Summit saw over 300 individuals participate in developing three white papers (on research, quality of life, and access to treatments) regarding the challenges and key issues facing the vision-loss community in 2020, and had nearly 11,400



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PHOTO: FBC Library

Cyclists excited to ride at the Cycle for Sight start line.



PHOTO: C.LLiK Photography

Last Call guests playing the fan-favourite game, Glasses On/Glasses Off.

viewers on Facebook. The white papers can be viewed at fightingblindness.ca/whitepapers.

Doug is a motivating, tireless, and inspirational fundraising executive. He's a translator of science and organizational missions to engage donors to spark innovation that impacts lives. Doug has over 30 years of experience at inspiring philanthropists to give \$1+ billion to organizations helping those in need, funding research to change lives, and rejuvenating communities. Doug's mission is to identify philanthropists' goals and match them to organizational priorities, creating transformational outcomes that help people and improve communities. He's active in various fundraising professional organizations, community not-for-profits, and boards. Doug has been a Certified Fund Raising Executive for over 15 years.

FBC is Canada's leading private funder of vision research. The organization offers hope to Canadians by identifying the best, most promising vision research that's driving treatments and cures for blinding eye diseases, and by advocating for Canadians to have access to the vision treatments that research has delivered. Its work focuses on the main drivers of blindness: age-related macular degeneration, glaucoma, diabetes-related vision complications, and inherited retinal diseases like retinitis pigmentosa, Usher syndrome, and Stargardt disease.

Over FBC's 47-year history, it has invested over \$40 mil-

lion to support vision research and education across Canada. This encompasses over 200 research grants which have led to over 600 new discoveries in areas such as stem cell research, neuroprotective therapies, technological developments, pharmaceuticals, and gene therapies.

FBC has worked with the CCB to prepare joint submissions to key government agencies to present the perspectives of people living with vision loss on government decisions and public policy. This work in the past year has resulted in three new research-delivered treatments to restore sight or prevent blindness being approved by the Government of Canada, and access to these treatments being approved for public health care funding in several provinces.

In 2020, FBC published IRD COUNTS, Canada's first socioeconomic study on the impact of inherited retinal diseases (IRDs), reporting on a \$1.6 billion impact for Canada's almost 21,000 people living with an IRD and their families. This report provides valuable statistics to support the advocacy efforts of the CCB.

In bestowing the 2021 President's Award, the CCB commends Doug and the team at FBC and offers our continuing support to their vision, inspiration, and commitment to eye disease research. Their approach to research and its results will serve as a continuing benefit to not only those Canadians living with vision loss, but also to those yet to be diagnosed. □

GPS apps for vision accessibility needs



BlindSquare Promo and Nearby Explorer Online provide for safe, reliable and independent travel by voicing directions, points of interest and descriptions of surrounding areas, both indoors and outdoors. Take advantage of these apps anywhere you go on Canada's largest network.¹



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The Power of Engagement: The CCB Builds a Stronger Future

BY JIM TOKOS, CCB 1st Vice President



The Canadian Council of the Blind (CCB) has been a mainstay in the visually-impaired community for over 75 years, facing some challenges along the way but embracing many opportunities as well.

The CCB has been blessed with strong, committed, and qualified leaders. Through this leadership, we have developed many programs to enhance and promote our members' abilities, including the Get Together with Technology (GTT) program, various sports programs, computer training, and more.

As the CCB stands strong on a solid foundation, we now look toward younger members and staff to take us into bold new directions in the future.

Dynamic individuals like Nolan Jenikov and Samantha Moore have fresh perspectives on where they feel the CCB should be headed.

"I'm interested in engaging our younger members," says Nolan, who runs a weekly GTT Youth Chapter. "They're so tuned into what's happening with regards to assistive technology. It's rewarding to see them gain confidence as they support each other during meetings."

"By engaging youth, not only are we getting them involved with more social activities, we're also helping them to gain life skills," says Samantha Moore, Coordinator of Public Relations at the CCB. "Developing key skills such as team-building will be helpful once they enter the working world."

As the GTT had already been harnessing the power of technology to host virtual meetings and training sessions, we were well-positioned once the pandemic hit

and we were confined to our homes. Tech-savvy people such as Nolan were able to leverage software platforms like Zoom to assist our more senior members as we moved their chapter meetings online. This allowed all of our members and participants to maintain social interaction while remaining safe.

This is a perfect example of a new and alternative perspective that will sustain the

CCB's growth into the future.

Our next step is to begin to engage younger members into the "business" side of the organization. Involvement on committees and advisory boards are not only key to the continuance of the CCB, they also provide excellent and enriching opportunities for growth of the members involved.

Leslie Dunford-Yee is a shining example of this. After becoming legally blind at age 48, Leslie decided that she wanted to get involved in the community. Now, she's chair of the CCB Peterborough Chapter, sits on the National Membership committee and the National Nominations committee, and volunteers for other organizations within her community.

"We all have the power to move forward," says Leslie. "We just need to find the right people and friends to help."

The CCB must develop in new ways if it is to remain a healthy and sustainable organization, especially with the ever-increasing complexities in the not-for-profit sector. By engaging young leaders with a fresh vision, we will secure our foothold in the community for years to come. □

Canadian Council of the Blind's Get Together with Technology Program Introduces Exciting New Initiatives

BY CORRY STUIVE, GTT National Program Coordinator



As many of you know, the Canadian Council of the Blind (CCB) has been offering an exciting program called Get Together with Technology (GTT) over the past several years. The CCB GTT program has enjoyed tremendous success across Canada.

Here's what some of the participants are saying about the program:

"I was nervous about trying to remain physically distant while paying for items with cash," says a GTT member in Vancouver. "GTT taught me how to do e-transfers in this time when it's necessary to be physically distant and difficult to exchange cash with ease."

"I hadn't even used an iPhone as a blind person a year ago," says an individual in the GTT Edmonton group. "Today, I'm using Dolphin EasyReader to read books, as well as WhatsApp, Skype, and FaceTime to keep in touch with family around the country."

"Through one of the other participants I met at GTT, I learned how to use Zoom on my iPhone," says a GTT participant from Ottawa. "Now I can have virtual visits with my grandchildren. It's so nice to have that face-to-face

interaction again, even if it's from a distance."

For those of you who may be late to the game, let me review the basics of GTT while at the same time introducing you seasoned veterans to some new and exciting goings-on.

The whole concept of the CCB GTT program is based on peer support and mentoring. Who better to teach the unique skills of adaptive technology to the blind and low-vision end user than other blind and low-vision folks who possess that knowledge? That's what peer support and the CCB are all about.

There are several components associated with the CCB GTT program. One important component are local meetings (subject to ongoing COVID-19 restrictions – please stay up to date with our blog for more details on when they become available).

We also offer a support list. Have a technical question? Ask it on the list and one of close to 300 members will in all likelihood come up with an answer or solution.

We offer a Buy, Sell, and Trade list for adaptive technology. Have tech that you don't need or want



anymore, but that could perhaps benefit others? Or looking for a new device? This is a great resource.

We have a Facebook page, Twitter page, and a blog so you can stay connected with the GTT program online.

The GTT program also includes one-on-one training. Are you new to technology? Need some extra help? Don't know what phone, computer, or software to buy? We can help. Simply call or write us at gttprogram@gmail.com or 1.877.304.0968 ext. 513.

As COVID-19 has forced us out of the traditional face-to-face meeting mode, at least temporarily, the CCB GTT has adapted by holding many group sessions via Zoom. Zoom is a platform that lets us gather and participate in meetings from the safety and comfort of our own homes. If you need some basic help in understanding how Zoom works, please call us and we can help with that, too.

Using Zoom has created some new opportunities that might not have existed, or at least been thought of, prior to COVID-19. We're now moving forward by offering some new specialized groups, including a youth group, a group for Android users, a Women in Tech group, and a low-vision group, to mention just a few. Please continue to check the blog to keep up to date on all the latest happenings.

And speaking of more info, if you'd like more information on the CCB GTT program in general, contact us at the divisional or national level and we'll get back to you ASAP.

Happy computing! ☐



GTT RESOURCES

GTT blog: gttprogram.blog
Support list: groups.io/g/GTTsupport
Buy, Sell, and Trade list:
ccb-tech-buyselltrade.groups.io
Facebook page: [@GTTatCCB](https://www.facebook.com/GTTatCCB)

Markido Inc. Helping to Make Presentations Accessible for All

BY MIKE POTVIN



Markido Inc. is an Ottawa-based company that specializes in software called Engage, which enhances PowerPoint presentations, with an emphasis on accessibility.

"We want people to be able to communicate information to all audiences in an understandable, digestible, and memorable way," says Sam Berns, CEO of Markido. "That absolutely includes people with disabilities and especially those with visual disabilities."

When designing the software, Berns sought direct input from the visually-impaired community regarding the accessibility features. He understood that using inclusive design principles makes a better product for all users.

For a number of years, Markido has been a valued supporter of the Canadian Council of the Blind and its Get Together with Technology (GTT) program. We would like to thank them for both their recognition and their generous support. ☐



First Sight-Restoring Treatment for an IRD Approved in Canada

BY DR. LARISSA MONIZ and FAY KNIGHTS



A significant milestone for the inherited retinal disease (IRD) community took place on October 14, 2020: Health Canada announced its approval of the first gene therapy treatment voretigene neparvovec (brand name Luxturna) for an IRD.

The newly-approved treatment is specifically for individuals with retinitis pigmentosa (RP) or Leber congenital amaurosis (LCA) resulting from mutations in the RPE65 gene, which lead to vision loss and eventually blindness. The RPE65 gene is important because it provides instructions that allow retinal cells to convert light to an electrical signal that's sent to the brain to generate vision. Mutations in the RPE65 gene lead to reduced or absent RPE65 functioning, blocking light signals and leading to vision loss. The newly-approved treatment delivers a working copy of the RPE65 gene directly to retinal cells, giving the cells instructions to generate light signals and preserving or even restoring sight.

"Lives will be transformed in Canada because of this groundbreaking treatment. For the first time, it means we have a treatment option, bringing hope to families affected by genetic mutations causing blindness," says Doug Earle, President and CEO of Fighting Blindness Canada (FBC).

For families like the Gandhis, the approval of this treatment has been years in the waiting. Sophia Gandhi is the mother of Zara, 10, who was born with blindness due to LCA from the RPE65 gene mutation. "Zara was diagnosed with blindness at six months old," says Sophia. "It was very difficult on our family. When we learned about Luxturna many years ago, we knew one day it must and

would come to Canada. The time has now come – this can change Zara's life."

Dr. Elise Héon, a clinician-scientist in the field of ocular genetics with the Hospital for Sick Children in Toronto (one of the sites for this treatment in Canada) and Zara's eye doctor, sees this milestone as a significant step forward. "Until now, patients like Zara had no treatment options and the progression toward complete blindness was inevitable," says Dr. Héon. "These families now have hope with the promise of a one-time treatment option that can improve or restore vision, especially night vision."

While this treatment has been approved by Health Canada, recommendations from the Canadian Agency for Drugs and Technologies in Health (CADTH) and the Institut national d'excellence en santé et en services sociaux (INESSS) are in negotiations for provincial health care coverage.

FBC, the largest private funder of vision research in Canada, urges all affected by an IRD and their families to help advance vision research by getting their genetic testing done and joining FBC's IRD Patient Registry. Genetic testing not only helps individuals identify if they can be treated, it also supports research into all IRDs.

For more information about Luxturna, genetic testing, or FBC's IRD Patient Registry, email healthinfo@fightingblindness.ca or call 1-888-626-2995. □



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

Living with Vision Loss



Welcome to the future of medicine





It's White Cane Week 2021 at the Canadian Council of the Blind

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 returning from the war and 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. Sadly, living in this era of COVID-19 where social interactions and gatherings aren't possible, CCB members across Canada will miss many of their usual events and sports competitions. To that end, the CCB has gone virtual in an attempt to fill the gap.

White Cane Magazine will be published on Feb. 10. The CCB will host four major

events through to the middle of February. White Cane Week's kick-off will be the Virtual Expo Forum (on the topic Assistive Device Programs) on Feb. 13 at 2 p.m., followed by the Vision 2021 Virtual Gala on Feb. 18 at 2 p.m., and bookended by the Vision 2021 Virtual Summits, which are scheduled for Feb. 17 at 2 p.m. (on The Impact of the COVID-19 Pandemic) and May 26 (on The Cost of Vision Loss in Canada) at 2 p.m.

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,



Doug Earle
President & CEO,
Fighting Blindness
Canada



Dr. Jane Barratt
Secretary General,
International
Federation on Ageing



Louise Gillis
President,
Canadian Council
of the Blind



Photo courtesy of FBC photo library.



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 dystrophies," 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. 

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

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 ther-

apies 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 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. 



Dr. Jane Barratt
Secretary General,
International
Federation on
Ageing



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

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

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 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 associated 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. 👁

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



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 partial-

ly-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.” 

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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.



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CCB Limitless Chapter
CCB Listeners Book Club
CCB London Chapter
CCB London Vision Impaired Curling Chapter
CCB Mississauga V.I.P. Chapter
CCB Ontario Visually Impaired Golfers Chapter
CCB Ottawa Blind Curlers Club
CCB Ottawa Chapter



- CCB Pembroke White Cane Chapter
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For more information or to reach a National Board member, please contact the Canadian Council of the Blind at our national office: Toll-free: 1-877-304-0968 • Email: ccb@ccbnational.net

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



Kelly and Company co-hosts Kelly MacDonald (right) and Ramya Amuthan.

Kitchen Confession host Mary Mammoliti.

The year 2020 was one filled with uncertainty and fear because of the pandemic. COVID-19 affected Accessible Media Inc. (AMI) as well.

Safety measures meant television production on AMI-tv and AMI-télé was shut down for weeks. Due to planning measures in place, AMI-audio was able to immediately pivot to continue producing *NOW with Dave Brown*, *Kelly and Company*, and *The Pulse* from the safety of the hosts' and producers' homes. We're very proud of the fact that we were able to get AMI-audio on the air quickly – and safely – to provide the blind and partially-sighted community with the latest information on COVID-19.

The pandemic didn't stop AMI from rolling out several exciting initiatives and celebrations throughout the year.

Employable Me won its third Rockie Award at the 2020 Banff World Media Festival. The series features job seekers who are determined to prove that having a physical disability or neurological condition shouldn't make them unemployable. Season 4 of *Employable Me* will debut in 2021.

This year, we also unveiled the redesigned, refreshed AMI.ca. Visitors can now enjoy a cleaner, more streamlined

layout highlighted by the recently redesigned AMI logo and featuring high-contrast blue and customizable accessibility settings for the blind and partially-sighted community AMI serves.

The COVID-19 pandemic has affected everyone's way of life, and AMI-tv reflected that in a series of documentaries like *Arts, Culture & COVID-19*, *Inside the Bubble: Health & Wellness During COVID-19*, *Powered Up: Empowered by Assistive Technology*, *Pandemic Performance: Conversations with Artists*, and *Paralympics Postponed: The Long Road to Tokyo*. We encouraged our on-air audio and television hosts to discuss their thoughts, fears, and tips for getting through the pandemic safely in segments called Real Talk. Real Talk has connected with the community through social media and will continue in 2021.

In July, AMI-tv debuted the first season of *Level Playing Field*. Hosted by Paralympian Greg Westlake, it highlights and celebrates the power of sport by introducing audiences to the athletes, community groups, health care professionals, and grassroots innovators who demonstrate a desire to help drive positive social change through sport.



Level Playing Field host Greg Westlake (left).



Employable Me job seeker Ariana.

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

Things were just as busy on AMI-audio in 2020. In addition to live broadcasts of *NOW with Dave Brown*, *Kelly and Company*, *The Pulse*, *Late Edition*, *The Neutral Zone*, and *The Gazette*, AMI added original podcasts to our broadcast platform. Emotional, funny, and informative, these podcasts offer an intimate peek into the blind, partially-sighted, and disability community in Canada.

Podcast titles include *Kitchen Confession*, hosted by celebrity culinary expert Mary Mammoliti; *Accessing Art with Amy*, hosted by Amy Amantea; *The Blind Reality* with Becki Zerr; *Low Vision Moments* with Jennie Bovard; *A Yogi's Guide to Health and Wellness*, hosted by Kevin Naidoo; *Into You* with Fern Lulham; and *Tales from the Halifax School for the Blind*, hosted by Terry Kelly.

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

Looking ahead to 2021, things continue to be busy for AMI-audio, AMI-tv, and AMI-télé.

New seasons of *Level Playing Field*, *Eyes for the Job*, *Employable Me*, *#IGotThis*, *Our Community*, *You Can't Ask That*, and *Mind Set Go*, as well as new episodes of *AMI This Week*, *Double Tap TV*, and original documentaries are on tap. New series include *Spirit to Soar*, a program celebrating the art of Indigenous members of the disability community; *Sight Seers*, which follows Mark Joly, a psychic who is blind, conducting otherworldly investigations in Nova Scotia; and the adventure series *By Hook or By Cook*, starring former freestyle motocross rider Bruce Cook.

We're also in the midst of planning a virtual event in the spring that will bring attendees up close and personal with our AMI talent!

AMI-télé continued to produce programming during the pandemic with its flagship show, *Ça me regarde*, using remote technology to keep everyone safe. New initiatives enabled close communication with the francophone public, including a new show, *Plan large*, hosted by

reporter Jessie Archambault, and weekly social media videos featuring our hosts and collaborators sharing their pandemic experience and encouraging viewers to keep well and safe. *La longue remontée* enjoyed wide media coverage. *Engagez-moi*, *Pas plus compliqué que ça*, *Mon guide yoga*, and *Des familles comme les autres* are AMI-télé original productions that encompass the subjects of health, lifestyle, employment, and family and community life.

Don't forget: AMI-audio, AMI-tv, and AMI-télé are all available as part of basic digital packages offered by most television providers across the country. If you have basic cable, you have access to AMI.

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

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

AMI's Research Panel serves as an ongoing feedback mechanism between AMI and the community. Canadians who are blind or partially-sighted are invited to join and share insights and opinions on accessible technology, TV programming, media consumption, and more through focus groups, online questionnaires, and telephone surveys. Join the AMI Research Panel today and help shape the future of accessible media. Register for the AMI Research panel by calling toll-free 1-855-839-4772 or visiting AMI.ca/research-panel.

Visit AMI.ca or AMItel.ca or email info@ami.ca to learn more about us.

As a longtime supporter and partner, AMI is proud to participate in White Cane Week 2021. □





COVID-19 Impact Survey Report

Canadian Council of the Blind's COVID-19 Impact Study Reveals Disturbing Reality for Canadians Living with Vision Loss

BY KEITH GORDON, PH.D., AND MICHAEL BAILLARGEON

This past year has been one unlike any other for us all, and particularly for people who are blind, deaf-blind, or partially-sighted. Our community has experienced economic, social, and emotional stress over and above that experienced by the sighted community.

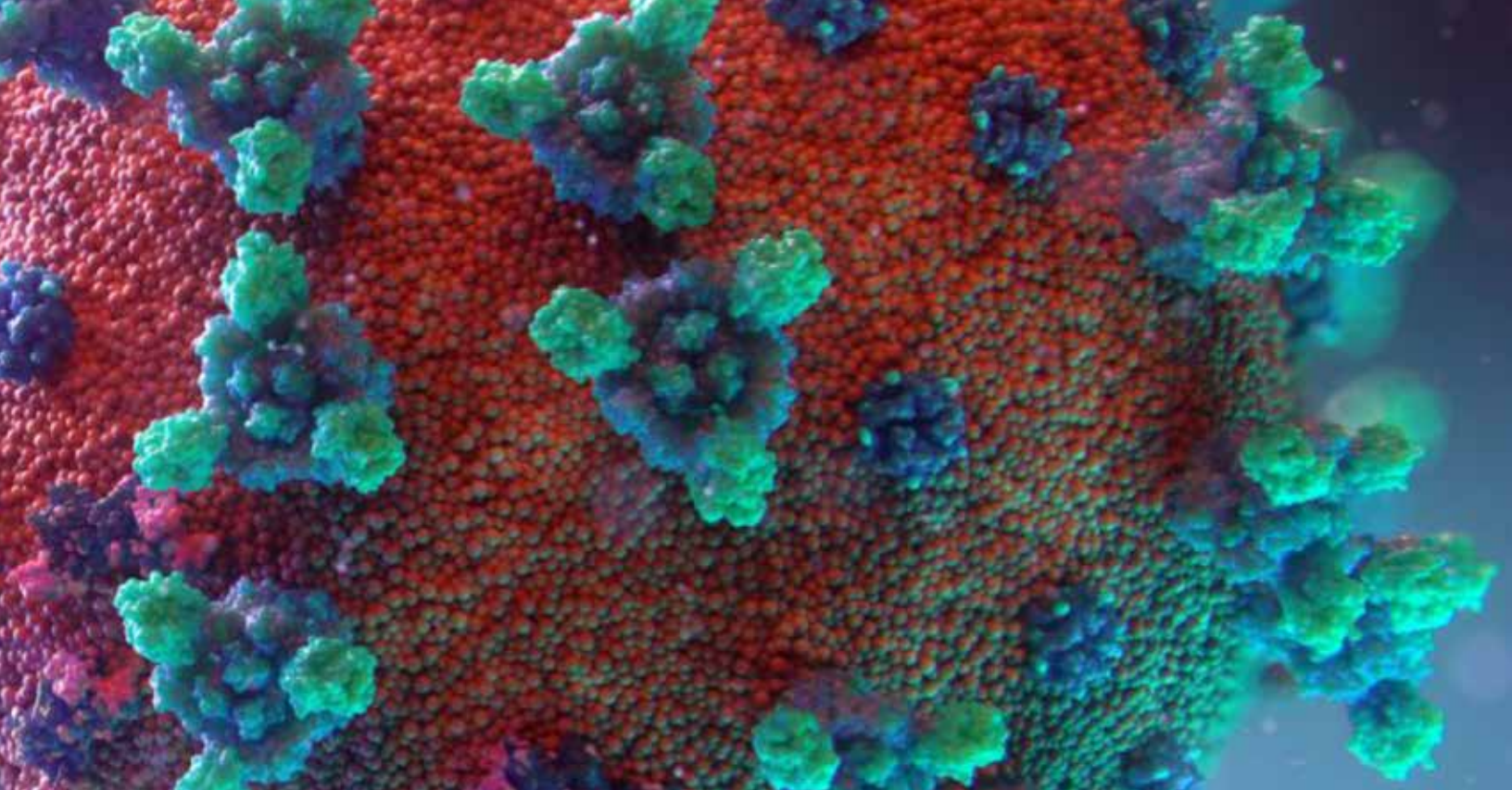
Very early on in the pandemic, the Canadian Council of the Blind (CCB) was receiving reports of challenges being experienced by people living with vision loss as they tried to observe government recommendations with respect to social distancing, wearing masks and PPE, and going out of their homes. It was clear that many Canadians who are blind, deaf-blind, or partially-sighted were being heavily impacted by the COVID-19 pandemic.

At the same time, it became apparent to the CCB that the many government initiatives and programs being announced in response to pandemic-related challenges were, for the most part, not taking into account what we see as the fundamental needs of not only our community, but of all people with disabilities. We perceived the

need for all levels of government to provide support and solutions to help those with vision loss get through these stressful times.

In order to provide governments with the advice they needed, it was determined that the CCB needed to survey the vision loss community in order to identify what those living with vision loss were currently experiencing due to the pandemic and what their specific concerns were. We wanted to make sure that the vision loss community would be provided with the support they need to weather the COVID-19 pandemic and that they wouldn't be left behind or forgotten.

Key results of the study showed high levels of stress in the vision loss community. Respondents were very concerned about social distancing – they were unable to see how far they were from others and were concerned that others didn't realize that they had vision loss and tended to come too close. Respondents felt unsafe when leaving their homes and felt shopping was unsafe. They



experienced both stress and anxiety with their inability to tell how far they were from others within the store and frustration when they couldn't adequately negotiate payment with cashiers, who are usually behind plexiglass screens, which are invisible to people with vision loss. As one respondent put it: "As a totally blind individual, I find that people whom I encounter while walking or shopping do not understand that I am unable to self-distance from others. Firstly, they regularly do not make me aware of their presence so that I can take the proper action. Secondly, people often approach me closely, not taking responsibility for self-distancing to protect me. Thirdly, the practice of controlling numbers in stores neglects the issue that I cannot maintain proper self-distancing when forced to line up either to enter the store or to reach a check-out. There is no messaging on the media about considering how to help those who cannot readily self-distance due to a disability."

Respondents were particularly concerned that the effect of the added stress from the pandemic on their mental health may cause them to become overwhelmed. One respondent expressed their concern quite poignantly 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."

Respondents reported being stressed about their inability to access a doctor or health care practitioner. Furthermore, they expressed concern that social distancing restrictions and patient-only medical appointments meant that they

wouldn't be able to have someone accompany them should they have to go to the doctor, clinic, or hospital. This was of particular concern to people who required a sighted guide to assist them with many of their activities. Additional concerns regarding access to medical services were expressed by this respondent: "Changing where you can get basic care done like closing of labs and having to go to unfamiliar parts of cities without any supports or technology is frightening. Also in rural areas there [are] no transportation services to get to the larger centres to receive medical attention. This has been a major issue across Canada and with volunteer drivers unable to drive, people are at risk and not receiving medical care they need."

Respondents also expressed concern that their inability to keep eye doctor appointments may cause them to incur additional vision loss. This was a significant issue for those having regular injections for the treatment of age-related macular degeneration or diabetic retinopathy.

Respondents were particularly concerned about their inability to meet their financial obligations and their inability to maintain their standard of living. Many who were asked to work from home had discovered that they didn't have the proper accessible devices and technology necessary to do their jobs from home, and that their employers had refused to provide or fund necessary equipment.

About half of the respondents indicated that they had a personal care worker entering their home, about half of whom weren't wearing proper personal protective equipment.

Asked to identify their current stress level on a scale of



1 to 10, 40% of respondents said they were experiencing more than moderate stress, with 29% rating their stress level at 7 or higher.

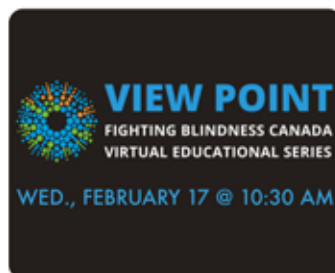
It's clear that the vision loss community is being heavily impacted by the pandemic. It's further evident that there's a need for immediate action from all levels of government to provide support and solutions to help those living with vision loss get through these stressful times. Governments, with the support of stakeholder organizations, must respond with urgency to the circumstances endured by those living with vision loss on a daily basis. All necessary steps must be taken to recognize the needs of this vulnerable community and to mitigate the harshest effects of the COVID-19 pandemic on them. This need was summed up well by a respondent who said: "I have not heard of any levels of government addressing the needs of blind or visually-impaired individuals as well as those with other disabilities. We need jobs, we need groceries, and we need to be able to live in dignity and to be considered."

The complete report on the CCB study includes detailed recommendations for all levels of government to consider. The report, entitled *The Survey Report on the Impact of the COVID-19 Pandemic on Canadians Who Are Blind, Deaf-Blind, and Partially-Sighted*, is available on the CCB's website and is fully accessible.

At the time of writing, the first Canadians were starting to receive the COVID-19 vaccine. Because of the challenges being experienced by the vision loss community, as identified in the CCB survey, the CCB is calling on government health authorities to ensure that people living with vision loss be given a priority position, close behind our heroic first responders and vulnerable seniors, with respect to being vaccinated against COVID-19. □

Note: Keith Gordon, Ph.D., is CCB's Senior Research Officer and Michael Baillargeon is CCB Senior Advisor, Government Relations and Special Projects

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What the CCB Means to Me

BY SAM BERNES, CEO, MARKIDO INC.



Shown here are Maryse Glaude-Beaulieu, Sam Bernes, Kim Kilpatrick and Albert Ruel at Markido's Engage booth, at CSUN in Anaheim, California on March 13, 2019.

I help run a software company and we build a PowerPoint add-in that makes it easier for people to create accessible presentations. But it didn't start out that way. When we first started, I'm ashamed to say that our software wasn't accessible. I had the good fortune of having an amazing client who sat us down and explained that our data visualization software made it harder, not easier, to access the information they needed to do their work. I knew then that we had to do better, but I didn't know how.

That's when I reached out to the Canadian Council of the Blind (CCB) for help. Over the years, members like Louise Gillis, Kim Kilpatrick, Rebecca Jackson, David Greene, Albert Ruel, Mike Potvin, Shelley Morris, Corry Stuve, and Samantha Moore have helped us create software that was not only accessible but that also helped others create accessible documents. That has pretty much been our mission since then – to help our clients create accessible documents so that everyone can access the information and fully participate in decision-making processes.

The Experience Expo during White Cane Week was a truly transformative event for me. I met so many incredible people and it was my introduction into the world

of the CCB, where amazing people help amazing people. Everyone I met was committed to removing barriers and unlocking the full potential innate in every person, and I knew I wanted to be a part of this in a real way. My next adventure with the CCB was a trip that five of us took together to attend the California State University, Northridge (CSUN) Assistive Technology Conference in Anaheim back in 2019. I've also been fortunate to participate on Get Together with Technology (GTT) calls over the years, and today in our software company I get the privilege to work alongside people who have worked for or volunteered with the CCB.

I see firsthand the amazing work that the CCB does each day and the impact it has on so many Canadians living with blindness and low vision. Working with the CCB has made our software better and it has also made our company better. You never forget someone who has helped you and for us, we can never forget all the help the CCB has provided us with and all the great people who make the CCB what it is. □



Talk Description to Me
with Christine Malec
and J.J. Hunt

The Talk Description to Me Podcast: Accessible Journalism at Its Finest

BY SHELLEY ANN MORRIS

Ever wonder what Joe Biden’s sunglasses look like? Or what colours the autumn leaves are? Or what Beirut looked like after the explosion? The *Talk Description to Me* podcast transforms visuals into words that people with vision loss can appreciate.

The podcast consists of conversations between Christine Malec (who’s blind) and J.J. Hunt (a professional audio describer). Malec poses questions about the visual context of current events and the world around us from a blind person’s perspective, and Hunt provides content-rich descriptions.

These visual elements need to be brought to life, as it’s often wrongly-assumed that visual aspects are understood by those who cannot see. Many things aren’t readily obvious simply by sound, and require more detailed description. For example, a gesture such as rubbing fingers together to indicate significant cost (‘show me the money’) isn’t always understood by someone who has never seen that gesture.

The *Talk Description to Me* podcast is description and more. The podcast came about as a result of Malec asking Hunt what different aspects of the world looked like during the COVID-19 pandemic. It all started when Hunt was invited to participate in Malec’s regular segment, *Curious Minds*, heard on the third Thursday of each month at 3:15 p.m. EST on *Kelly and Company* on AMI-audio. The segment is a deep dive into arts and culture from a blindness perspective. Hunt and Malec soon realized that there’s a distinct gap between current events and the ways that they’re described.

While audio description is becoming increasingly available on TV shows, during live events, and at the movies, more work must be done to increase accessible journalism. As audio description has been around for a long time, those who use it have a basic understanding of how

it works, and so it can now be applied to current events.

According to Hunt, when audio description is done well, it can be quite seamless, augmenting the experience of those who use it. Descriptions are woven in and out of the dialogue and sound effects, with the describer’s voice being part of the landscape while remaining distinct enough to be heard. Descriptions of subtle facial expressions can make a big difference to those who cannot see or who appreciate these visual cues. Hunt notes that those with autism also often appreciate audio description because of their difficulty reading facial expressions, non-verbal cues, and emotions. The range of people who benefit from audio description is vast. And once they start listening to audio-described content, people with low vision soon realize how much they’ve been missing.

Talk Description to Me features a wide range of topics. Wild fires, tornadoes, protests, and images from 9/11 are some of the more sobering pieces of content. On the lighter side, movie trailers, baseball in the COVID-19 era, text bubbles on Facebook, and pandemic-inspired advertising are also featured. All subjects contain descriptions of items that the sighted world often takes for granted.

No matter what’s being described, Malec notes that neutrality is central to the podcast and that the audience will have their own reactions to the descriptions provided. Different people will naturally have different responses if the description comes from a place of neutrality. Malec and Hunt work carefully and sincerely to maintain neutrality, which is quite a feat when describing Donald Trump’s hair or the chilling images that were seen in the wake of racial unrest.

Subject matter for *Talk Description to Me* comes largely from what’s current, what’s describable, listener feedback, and subjects that the creators feel would be of interest to others. A listener requested a description of ‘jazz hands,’ a kind of cheeky, celebratory Broadway dance move that involves twisting your hands with spread fingers, accompanied by wide-open eyes and an open-mouthed smile. The most difficult podcast to produce was the description of the protests that took place in Portland, Oregon. It was challenging to maintain neutrality, composure, and professionalism. It’s often the subtle images that are the most profound, such as mothers holding signage in a line at a protest. Climate change, politics, the pandemic, and race are all pivotal issues and can be difficult to describe. With description provided by the *Talk Description to Me* podcast, visually-impaired people can make more informed choices in taking a position.

Hunt notes that it’s hard to remain composed when describing emotionally-heavy moments in which people

aren't being respectful to each other. While the annual Toronto Pride Parade is fun to describe, the poignant messages appearing on the signage carried by parade participants take a tremendous amount of ability to convey.

With Malec's background in journalism, the arts, and a wide variety of interests combined with Hunt's training and over 20 years as a professional audio describer, audiences can be assured that they'll be both entertained and better-informed after each episode. To listen to the *Talk Description to Me* podcast, visit www.talkdescriptiontome.com. The podcast is also available on all podcast platforms.

Email: talkdescriptiontome@gmail.com

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Support the podcast on Patreon: www.patreon.com/talkdescriptiontome (if you'd like to support financially) □

Blind Skier Wants to Share Backcountry with Other Visually-Impaired People

BY BEN MUSSETT, CBC News

When Tyson Rettie started to lose his vision two years ago, he had to cut short his career as a backcountry ski guide in B.C.

But with the help of his friends, he hasn't stopped skiing.

How does he do it? Rettie says it depends on the terrain.

If he and his friends are skiing an area with a large number of trees and other obstacles, he'll ski close to someone who "micromanages" him, calling out each turn Rettie must make.

The 29-year-old has a rare form of Leber's hereditary optic neuropathy, which can lead to a severe loss of central vision. The condition first affected only his right eye, but later both. Rettie says he has no central vision but has some remaining peripheral sight, though it's severely limited.

Based in the East Kootenay community of Invermere, Rettie prefers wide open alpine terrain where a buddy will describe to him what to expect at the top of the run. Sometimes he'll simply say: "You've got nothing to hit for 400 metres." Then once his friend has reached the bottom, he'll begin calling out to Rettie, who follows the voice down the mountain.

Backcountry skiing is an experience few blind people enjoy. Rettie hopes to change that with the new Braille

Mountain Initiative.

"I just thought: If I'm doing this, why can't others?" he told Chris Walker, host of CBC's *Daybreak South*.

The non-profit initiative plans to give other blind and visually impaired people the opportunity to experience the sense of freedom and independence that backcountry skiing affords. While resorts often offer guided skiing for the visually impaired, he says his initiative would be the first to provide a backcountry experience for blind skiers.

Re-learning the ropes

Rettie admits it took some time getting used to skiing without the advantage of sight.

His first season back on the hill was a "constant adjustment period." Every little bump and undulation tired him out because he had no way of anticipating it. And learning how to put complete trust in his guide wasn't easy either.

"It definitely took me a while to build the confidence to just say, 'OK, there's nothing to hit? If you say so,'" recalled Rettie.

One of the largest obstacles for blind people who are interested in skiing is likely finances, according to Rettie. A 2019 report from the Canadian National Institute for the Blind found that more than 70 per cent of working-age blind or partially sighted people in Canada are unemployed.

But there's also a "public perception issue," he says.

"The majority of people don't have a great understanding of what blind and visually impaired people can be capable of."

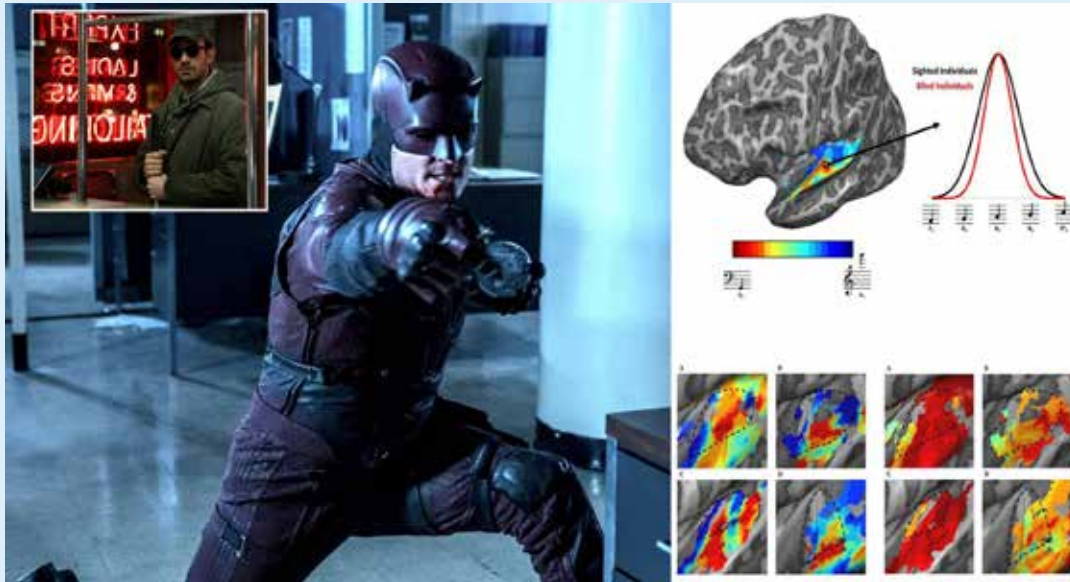
'Blind skiers doing rad things'

He hopes Braille Mountain will challenge misperceptions and "inspire newly blinded people to really take on the challenges that they had thought to not be possible."

"This is a more interesting story than just rad skiers doing rad things in the mountains," Rettie said. "These are rad, blind skiers doing rad things in the mountains. I think that's a valuable thing."

Braille Mountain's first backcountry trip — a partnership with Sorcerer Lodge, just north of Revelstoke — is slated for next spring. □





Blind People’s Brains Rewire Themselves to Help Them Track Moving Objects by Sound, Study Shows

BY ALEX MATTHEWS-KING

Enhanced hearing allows the visually-impaired to tune into subtle changes of frequency to track movements.

For the first time, scientists have shown how changes in the brain explain improvements to other senses — a phenomenon that has inspired comic book superheroes like the Marvel character Daredevil.

Some visually impaired people are able to train themselves to use clicks as a type of echolocation to detect obstacles.

The latest research from the University of Oxford and a number of US universities tracked people who were blind at birth or lost their sight as children.

They found their increased abilities may be possible because their hearing is much more finely tuned to variations in frequency.

Anyone who has heard a passing ambulance or police siren will be familiar with the way the sound appears to change pitch.

This phenomenon, known as the Doppler effect, is caused by a relative change in frequency of the soundwaves.

Being tuned into subtle differences in everyday noises may help blind people interpret their surroundings.

“For a sighted person, having an accurate representation of sound isn’t as important because they have sight to help

them recognize objects, while blind individuals only have auditory information,” said Kelly Chang, one of the study’s authors from the University of Washington.

“This gives us an idea of what changes in the brain explain why blind people are better at picking out and identifying sounds in the environment.”

The findings are published in two papers. One study in the *Journal of Neuroscience* used MRIs to scan the brain activity of blind subjects and test how finely tuned their neurons were to subtle changes in frequency.

The second study, published in the journal *Proceedings of the National Academy of Sciences*, looked at how a region of the brain devoted to tracking moving visual objects in sighted people is rewired to focus on tracking these auditory movements.

Researchers also studied two people who had been blind from infancy but had their sight restored thanks to surgery as adults. In these cases, this tracking region of the brain, known as hMT+, was able to perform this role for visual and auditory movements.

Professor Ione Fine, a psychologist at the University of Washington and senior study author, said this was the first study to show these changes in the auditory cortex.

She said: “This is important because this is an area of the brain that receives very similar auditory information in blind and sighted individuals. But in blind individuals, more information needs to be extracted from sound — and this region seems to develop enhanced capacities as a result.

“This provides an elegant example of how the development of abilities within infant brains is influenced by the environment they grow up in.” □

Navigation App Breaks Down Barriers for the Visually Impaired

**BY COLLEEN ROMANIUK,
Northern Ontario Business**

Jeff Godfrey is doing his best to ensure a barrier-free Canada.

The general manager of Y4U Technologies in North Bay has created a platform to solve the issue of building accessibility for those who are blind or partially sighted.

He discovered that high unemployment rates and low incomes are persistent problems among this demographic. One of the reasons for this is inaccessible workplaces.

After Bill C-81 was passed in June 2018, Godfrey took a closer look at the accessible building models currently available to the public. He realized that he had the chance to create something, using a sustainable development model, that would address the problem that exists with building navigation.

“I saw an opportunity to innovate on the existing information and technology that we had to have a positive social impact,” said Godfrey.

Working with his employer, SRP Building Products, Godfrey and his business partner, Marc Rayner, started to develop AccessiBuild, an indoor navigation system geared towards the visually impaired, in 2019.

The team uses architectural software to create detailed digital maps of physical spaces. The maps are then uploaded onto the platform and made available for download.

Anyone who downloads the mobile app on their phone can access the blueprints.

Although the creators are targeting those with visual impairments right now, anyone can use it. They hope to continue to adapt the software in the future for other demographics, including people who use wheelchairs or speak other languages.

Distance and bearings measurements can be customized to suit the user’s needs.

For example, the app can tell the user how many steps to take to the next door, and whether they should orient themselves left or right.

Using SRP’s LiDAR technology, which uses light detection and ranging, the company builds 3D models of spaces that are accurate up to three millimetres.

The end product is a streamlined app that makes navigating indoor spaces much easier.



The company’s goal is to practice sustainable development. In other words, they want to create technology that will have a positive impact on the world socially, economically, and environmentally.

AccessiBuild is meant to be less cumbersome and expensive than existing technologies on the market.

3D models of physical spaces produce huge data sets which need to be converted and compressed to be useful to someone without access to architectural software.

Godfrey and Rayner have sought to simplify the process.

AccessiBuild is free to use, which is important for those without much disposable income. Buildings will pay an initial fee to have their layouts mapped.

The company has been working with various organizations and local users to test the platform.

Brian Bibeault, committee chair of the Municipal Accessibility Advisory Committee in North Bay, has been acting as the company’s main tester, providing valuable feedback and guidance throughout the development process. CNIB Sudbury’s program lead for accessible technology, Victoria Francis, has also been on board.

Godfrey has built nothing into the software that they haven’t approved first.

“I can’t imagine the difficulties that they have as a sighted person,” said Godfrey. “We’ve had to make adjustments, but the feedback has been very positive and encouraging.”

The company has also opened up testing to tech trainers in the Canadian Council of the Blind.

The software was launched this year at 176 Lakeshore, Co-Working Offices, which also happens to be the first AccessiBuild-enabled building on the platform.

The commercial space is “very inclusive and community-oriented,” so Godfrey figured it was a great place to develop this kind of software. □

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As we celebrate White Cane Week 2021, the Canadian Council of the Blind (CCB) and its 85 chapters across Canada wish to express their most sincere gratitude to all of our sponsors, stakeholders, and friends for their contributions and ongoing support.

White Cane Week 2020 was still in the recent rear view mirror when the COVID-19 pandemic decimated our norms and played havoc with our lives. While it certainly

affected – and continues to affect – us all, it has been particularly hard on those living with vision loss. Your generosity during these difficult times was very important to us and has never been more highly appreciated.

Your continued presence is necessary for the CCB and our celebration of White Cane Week, including this year's virtual events: the Vision 2021 Forum, the Vision 2021 Summit, and the Vision 2021 Gala. □

See You at White Cane Week 2022



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