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# VISIONS

Canadian Council of the Blind Newsletter

October 2018

“A lack of sight is not a lack of vision”



## President's Message++



*1Louise Gillis - CCB National President*

Welcome to the fall season! If weather is like what the summer was we should expect lots of sunshine. The Canadian Council of the Blind (CCB) chapters across the country will have all started up preparing for activities and events over the next number of months. As 2019 is the anniversary of the CCB I anticipate many are considering ways to celebrate in their communities and demonstrate to everyone our “abilities” rather than our disability.

It is now the season for all sports activities to get started. Have fun, get exercise, socialize, and learn or assist in the GTT program so that we can lead a more productive lifestyle.

September has been very busy at the National level as well. Meetings were held with the Biosimilar Working Group ([biosimileroptions.ca](http://biosimileroptions.ca)). The Biosimilars Working Group is a key collaboration of diverse organizations, registered health charities, and health care advocacy coalitions who are dedicated to ensure that good outcomes for patients are at the center of health policy in Canada, specifically in the biologic medication treatment.

These medications are used by many of our members for the disease processes that we need to deal with on a daily basis. This, the reason for our participation, as per our mandate – “improving the quality of life for those who are blind and in the prevention of blindness”.



Both our Advocacy and Membership committees met in September which will continue throughout the fall. Should you have advocacy items you would like the committee to look into contact Pat Gates at

advocacy@ccbnational.net. Some of the current topics of discussion were the possibility of a National Pharmacare Program urging members to take part in consultations in communities over the next while. Also the concern of Greyhound service in Western Canada was a hot topic. Regarding ideas of how to attract new members may be sent to Co-Chairs Heather Hannett (hjhannett@telus.net) or Jim Tokos (jtokos@ccbnational.net).



The Bylaws committee continues to work toward making required changes to comply with the CNCA. This process does require a great deal of work and thank you to Mike Vrooman for leading the committee.

We continue to work with other groups of and for the

Blind to help improve the quality of our lives, the prevention of blindness and awareness of the organization. This involves meeting with government officials at all levels, community organizations, letter writing to ensure we continue to receive reading material of our choice plus much more. We continue to work with the International Federation on Ageing (IFA) on the Eye See You campaign, as we all know blindness has no limits of age, gender, etc.

There are lots of interesting articles in the newsletter. We encourage good new items, photos, or interesting articles that your chapter (such as dinners, awareness tables, sporting events,) are doing for the newsletter.

Louise Gillis, National President



# Announcements

## Two Important Days++

### October 11, 2018 – World Sight Day

The World Sight Day is the most important advocacy and communications event on the eye health calendar. Observed annually on the second Thursday of October, it is a global event meant to draw attention on blindness and vision impairment.



Around 253 million people live with vision impairment worldwide, of which 36 million are blind. The vast majority live in low-income settings. More than 80% are aged 50 years or above. More than 80% of all visual impairment can be prevented or cured.

During this World Sight Day celebrations the World Blind Union provides the following advice and call for action:

- It is important for all to have their eyes screened once a year in order to avoid preventable causes of blindness.
- Governments should allocate appropriate budgets across the world for vision health.
- WBU also encourages radio and television campaigns to sensitize the public about eye conditions and interventions.

### October 15, 2018 – White Cane Day

The mission of White Cane Day is to educate the world about blindness and how the blind and visually sighted persons can live and work independently while giving back to their communities.

On this year's White Cane Day, October 15, the World Blind Union emphasizes that trainings and awareness campaigns towards the promotion

of mobility and orientation using the white cane guarantee autonomy to blind and partially sighted persons to choose places they would like to go to and to participate effectively in their communities.

You can read the WBU's entire press releases here.

<http://ccbnational.net/fresco/wbu-statement-on-the-world-sight-day-2018/>  
<http://ccbnational.net/fresco/wbu-statement-on-white-cane-day-october-15-2018/>

If you would like even more information please visit

[www.worldblindunion.org](http://www.worldblindunion.org)

## GTT at the Annual CNIB Technology Fair++

On Thursday September 27 members of the blind/low vision community, family and friends, educators, vendors and community partners gathered for the annual CNIB Technology Fair. This event took place at Ottawa's City Hall. The room was filled with booths, offering everything from technology solutions that assist people living with vision loss and beyond. Ottawa's blind/low vision community was also well-represented with a host of services, as well as the Ottawa CCB Chapter and Get Together With Technology Program.

Kim Kilpatrick, GTT Program Coordinator and some GTT program participants were on hand to answer questions and provide information about this innovative, peer-driven group where people could learn to use all kinds of technology for increased independence. For example, those who stopped by the booth saw how any iPhone with Voiceover enabled would assist a blind person to read mail, find a bus stop, read short printed text aloud, take a picture, access the internet, use Social Media, attend school, and send a text. Whether blindness/low vision was life-long or recently-diagnosed, there was something for everyone!



*2Kim Kilpatrick at the 2018 CNIB Technology Fair*

Other kinds of technology (both high and low tech) were also demonstrated. Many visitors felt encouraged and said that they would follow up on what they had learned about GTT's blog posts, one-to-one drop-in sessions, monthly evening meetings and/or monthly conference calls. For more information, please contact 613-567-0311 or (toll-free) 1-877-304-0968

By Shelley Morris and Kim Kilpatrick (Picture from Fran Cutler)

Picture shows a very large GTT sign with GTT program Coordinator Kim Kilpatrick using a keyboard paired with an iPhone.

## CCB President Advocates for Patients at International Conference ++



In August, longtime Canadian Council of the Blind (CCB) partner, the International Federation on Ageing (IFA) hosted delegates from 75 countries at the 14th Global Conference on Ageing, in Toronto. The conference focused on critical issues facing older people today and for future generations. A diverse range of topics on ageing, which included a focus on vision were addressed and debated, guided by insights from thought leaders, new research, and real-world examples.

CCB President Louise Gillis was invited to participate in a panel discussion with experts from the World Health Organization, the IFA, and Canada's leading ophthalmologists. Rooted in ageism is the false and problematic myth that vision deterioration is just a part of 'normal' ageing. Vision loss is not an 'ageing issue' yet among adult at-risk populations there is a relatively low-level awareness of the need for regular eye screening, symptomatology of eye diseases and access to safe and effective treatments.

The panel discussion explored the relationship of vision-loss and declines in the health and the wellbeing of older populations, while focusing on important access, screening and policy issues that are threatening an individual's ability to optimize vision health.



*3Louise Gillis at the IFA 2018 Conference*

“Ensuring the voice of the patient is heard loud and clear is always an objective for me,” says Louise Gillis, CCB President. “With such a high profile conference, this was an important opportunity to not only highlight concerns and issues from the vision community, but to help establish an actionable framework that in collaboration with various stakeholders, we can achieve.”

The vision symposium at the conference was a marquee event that put ‘vision health’ on the priority list for Canadians. Through their ongoing work on the Eye See You campaign, the CCB and the IFA are a driving force, advocating for the rights of all patients. New advocacy initiatives are underway and the groups encourage you to visit [www.eyeseeyou.care](http://www.eyeseeyou.care) to ensure your voice is heard.

## CCB Health & Fitness October Update!++

Thanks to everyone who participated in our September Mindful Eating Challenge. We received some great feedback from across the country.

What have you learned from examining your own eating habits? Have you made any tweaks? Have any questions?



As always, it isn't a one size fits all answer, it is about being self aware and making little changes over time. Small changes in our lifestyle habits can have huge payoffs!! What's the old saying? Slow and steady wins the

race!! Keep being mindful and looking for opportunities to make healthy choices.

## FITNESS TRACKERS

As we turn the page on a new month, I got thinking about the number of CCB members out there that either:

-use their smartphone's GPS or accelerometer and an app, to measure their activity -use a dedicated activity tracker or fitness wearable, such as a gps watch, heart rate monitor, fitness tracker (fitbit, garmin, polar)



We all love technology and CCB Health & Fitness will be looking at this a bit more in depth as we move forward.

We would LOVE and appreciate your feedback.

Please send Ryan an email letting him know what technology you use to keep track of fitness; you phone, a dedicated fitness wearable, or none at all?

[ccb.healthandfitness@gmail.com](mailto:ccb.healthandfitness@gmail.com)

As always, we welcome feedback and suggestions on topics and challenges moving forward!

## CCB Chapter Update++

Hands of Fire proudly welcomes you to our third annual fundraising event: It's in the Fingertips – A Night of Art and Music! Hands of Fire is a not-for-profit organization and a chapter of the Canadian Council of the Blind which

offers sculpture classes to blind and visually impaired individuals. We are a Toronto-based group comprised of a number of talented blind and visually impaired artists who are thrilled to showcase their amazing and diverse works of art to the greater Toronto community in this fundraising event.

This year's fundraiser will be hosted at Jumblies Theatre, located 132 Fort York Boulevard, Toronto, ON M5V OE3. This downtown gallery space is steps from public transit and easy to access. Sculpture made by the artists will be on display and for sale, with the artists present to socialize and speak about their art. We are excited to announce that this year's fundraiser will include live musical performances by members of the blind and visually impaired community as well! With great art, music, a sociable and friendly environment, as well as food and drinks, this night promises to be one to remember.



*4Kangaroo by Susanna*

On behalf of Hands of Fire, we cordially invite you to come visit us this November 10 at Jumblies Theatre for a night of art and music, and all for a great cause!

CCB Chapter News:++

CCB Chatham/Kent Chapter: The past 14 months have brought about the establishment of a new Chapter, customized Chapter logo, creation of our Mission Statement “providing support, information and social activities for all our members”, the recruitment of the current 40 members, both blind or visually impaired and sighted, grant writing including budget development and submission, 3 fundraising events, 2 of them very successful and the other one I’ll classify as a learning experience while maneuvering through the Municipality rules, regulations and by-laws.

Every Chapter member had the opportunity to participate in the following events – golf, lawn bowling, self-defense classes, mini golf, horseback riding, game day, trivia night, pot lucks, BBQs, monthly bowling,



Christmas get-together, Pizza party, Elmira Maple Syrup Festival bus trip, volunteering at the information booth for RetroFest, and manning the information table at various senior awareness events.

Our Chapter meetings have had guest speakers from the Canadian Mental Health, Police Department, Hydro Rebate Program representative, Heart and Stroke and Self Defense instructors.

It’s been quite a ride!

Kathie & Dave

# US House of Representatives Passes Marrakesh Treaty Implementation Act Treaty Now Awaits Presidential Action ++

Washington, DC (September 25, 2018): The United States House of Representatives has passed the Marrakesh Treaty Implementation Act (S. 2559), which makes modest changes to copyright law that will bring the United States into compliance with the terms of the Marrakesh Treaty. The Senate gave its advice and consent to ratification of the treaty and passed the implementing legislation on June 28.



“For almost a decade now, the National Federation of the Blind, our partners, and other advocates have worked to bring the Marrakesh Treaty into being and into force,” said Mark A. Riccobono, President of the National Federation of the

Blind. “Today we applaud the United States House of Representatives for its passage of the Marrakesh Treaty Implementation Act. We now urge President Trump to sign this implementing legislation, and to order the State Department to deposit the instrument of ratification with the World Intellectual Property Organization as soon as practicable. We are closer than ever to the day when blind Americans will have greater access to the world’s knowledge, in many of its original languages, than we have ever had in human history.”



# Introducing the Doro 824++

It's the smartphone designed to make mobile more accessible. And it's available exclusively at Bell.

## Simplified user interface

With specially designed apps and an easy-to-read 5" HD screen, it's easy to use email, access your camera, browse the Web or message your contacts. Plus, the Google TalkBack feature helps low-vision users navigate. The Doro 824 is intuitive and understandable with larger fonts and a simplified menu.



## Safety and support features

Stay safe with a dedicated emergency assistance button that dials a predefined contact. Step-by-step guides and videos will coach you through the basic features, helping you understand your new phone. The My Doro Manager app lets your relatives or caregivers remotely manage settings, share photos, set up accounts, add calendar appointments and more – all done remotely.

## Modern design

The stylish, accessible design combines the simplicity of basic phones with the more advanced features of smartphones. Ergonomic and grip-friendly, the Doro 824 comes designed with physical buttons, including an emergency button.



## HD camera and sound

Take beautiful pictures with the 8-megapixel camera. It's easy to capture the moment by pressing the physical camera button. Plus, with the 2-megapixel front-facing camera and the Google Hangouts app, you can stay connected through video chat.

Need some extra help? The Doro is hearing aid compatible and provides loud, crystal clear sound.

Doro 824 customers who self-identify as having an accessibility need qualify for an \$8.54 monthly bill credit. Please let your Bell customer service representative know when activating your phone, or contact the Bell Accessibility services centre.

Accessibility add-on: complimentary 2 GB of data per month for qualified customers with hearing, speech or visual accessibility needs.

For more information, please visit:

[https://www.bell.ca/Mobility/Products/Doro-824?INT=MOB\\_mobdevpg\\_BTN\\_poplink\\_Mass\\_051016\\_mb\\_details](https://www.bell.ca/Mobility/Products/Doro-824?INT=MOB_mobdevpg_BTN_poplink_Mass_051016_mb_details)

## Bank Note Reader Update++

Today, the Bank of Canada announced that it will begin to phase out the bank note reader program. The bank note reader is the handheld device that identifies denominations through machine readable codes.



As technology continues to evolve, the Bank has determined that there are more modern devices that can be used.

For those with a smartphone or tablet, the Bank has evaluated apps currently on the market, and both Seeing AI and NantMobile Money Reader quickly and reliably denominate Canadian bank notes.

There are several benefits to using apps: they are free and easy to download and try out; they are easy to update as new bank notes enter circulation; and instead of a single function device like the bank note reader, smartphones and tablets have built-in accessibility features that can be used for various needs.



The bank note reader will continue to be available for a time, but no further upgrades are planned and the reader will not be compatible with the next generation of vertical bank notes. A number of bank note accessibility features will continue to help the blind and partially sighted recognize all five denominations with confidence. They include: the tactile feature, large high-contrast numerals and use of distinct colours for each denomination.

The Bank is also issuing a recall of the latest model of the bank note reader to upgrade and improve its performance with the polymer notes currently in circulation.

Those who've received this model of the bank note reader will be contacted by telephone and offered an upgraded device. A "swap" approach will ensure that individuals are never without a reader.

## Donna's Low Tech Tips: A scam alert++

Today, I'd like to introduce you to my scam alert.

Those emails asking you to login and verify your username and password that appears to be coming from your bank or insurance company.

If the email in question that you have received seems to be from a bank or insurance company that you do not do business with then you are okay. Just delete it and move on.

On the other hand if the email in question is from a bank or insurance company that you do business with; then by all means you can read it but my advice would be to also delete it.



No bank or insurance company would ever send you this type of email.

Not sure? Then just visit your bank.

Ask them to verify that they never sent you such an email. You could also call to verify as well.

Some of these types of emails may also go as far as to ask you to provide such details as your date of birth and account number.

Just delete this email and move on.

What would happen if you were to respond?

The simple answer would be trouble, lots of trouble, and now you have given a scammer out there carte blanche to hack into either your bank account and/or your very own computer system.



In the News

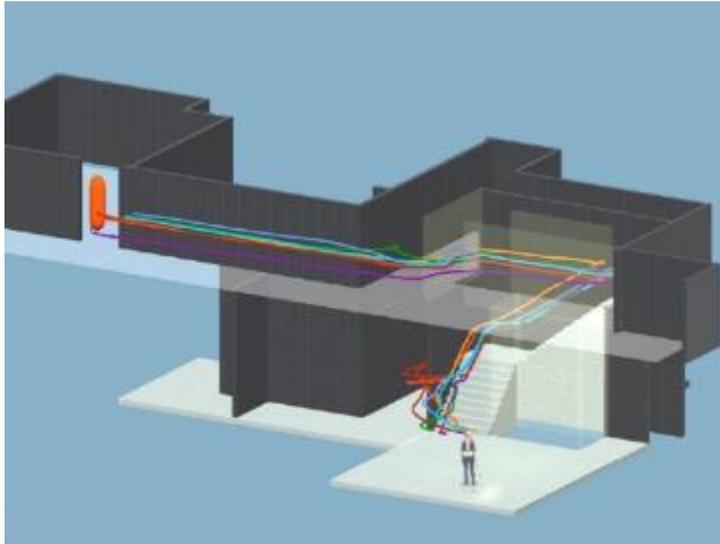
## HoloLens can now guide the blind through complicated buildings

The headset's ability to map a space and talk people through it may prove more important than the mixing-imagery-with-reality stuff. ++

HoloLens, Microsoft's pricey face computer, is made for mixing digital images with the real world. But a group of scientists found it's really good at a totally unanticipated application: helping blind people find their way through buildings and offering a better sense of where objects are around them.



The researchers, at the California Institute of Technology, created a new guiding app for HoloLens by taking advantage of the device's real-time room and object mapping capability, as well as speakers that can make audio seem to be coming from different points in three-dimensional space. They used these features to map a complicated path through a campus building and created a virtual guide that helps a blind person navigate it, calling out directions like "Follow me" from what seems like a meter or so ahead of the person, according to work recently published on the bioRxiv website.

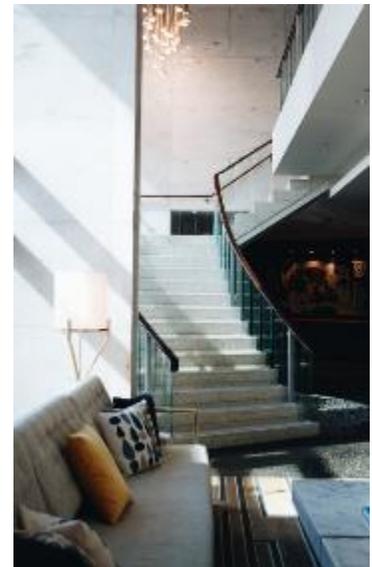


5 This render show the actual paths taken by the users in the navigation tests (image from techcrunch.com)

An accompanying video shows how this plays out in reality. A female voice directs a HoloLens-wearing study subject, who is blind, by saying things like “Railings on both sides,” “Upstairs,” and “Right turn ahead.” The man follows the commands, walking easily from a first-floor lobby up a set of staircases, around several corners, and past a few doorways until he arrives at a room on the second floor.

He’s one of seven subjects who tried the application. All got to their destination on the first try, though one briefly got off track. Markus Meister, a professor at Caltech and coauthor of the study, thinks the research could eventually lead to a device that could be offered to visually impaired visitors at places like hotels or malls, helping them get around unfamiliar areas more easily. There are already some tools that can be used this way outdoors, such as turn-by-turn mapping apps—but indoors, as Meister notes, there aren’t as many options.

The World Health Organization estimates that 253 million people are blind or visually impaired, so the potential market for such an application could be huge. But there’s still a lot of work to be done. For now, any routes from one point to another must be scanned in advance, and there isn’t a way to track other people who might walk through the space as the HoloLens wearer is navigating it.



But the study subject in the video, at least, was impressed with the work thus far. “That was pretty cool,” he says, chuckling, at the end of the clip.  
By Rachel Metz

# Hope for new macular degeneration treatments buoys patients++

Sometimes it starts with wavy vision. Objects appear distorted. Familiar faces go blurry.



Sean Teare, a 48-year-old health care consultant from Duxbury, struggled to read menus in dimly lit restaurants. After a battery of tests, his optometrist told him he had age-related macular degeneration, or AMD, an eye disease that afflicts more than 9 million Americans and can cause serious vision loss. "It came as a complete shock," said Teare.

The prevalence of the condition is rising as the population ages. The number of early-stage cases for those 50 and older is projected to nearly double to 17.8 million in the United States by 2050, according to the Centers for Disease Control and Prevention. For baby boomers, who are living longer than past generations and fiercely prize their independence, it's a dreaded diagnosis that threatens to rob them of everyday functions such as reading, driving, cooking, or watching television.

With the increase in cases has come a burst of research activity. There's currently no cure for the disorder, and no treatment for its most common form, which accounts for 85 percent of cases.

But scientists in Massachusetts and around the world are experimenting with dozens of drug candidates, including about 20 in clinical trials that work to preserve vision and, ideally, restore sight. They include not only well-established drugs, such as repurposed statins, but also new approaches such as gene therapies, stem cell treatments, and medicines tailored to the genetic makeup of patients.

"We're close to seeing some important findings," said Dr. Joan Miller, chief of the ophthalmology department at Massachusetts Eye and Ear Infirmary in Boston.

The disease, considered the leading cause of blindness in older Americans, is triggered by fatty deposits that damage a spot in the retina called the macular, which lets the eye see fine detail. Its rate of progression varies. Some patients don't experience vision loss for many years; others lose sight in their central field of vision, inhibiting their ability to see straight ahead, but retain peripheral vision.

Patients with a more severe form of the disease can receive periodic injections of an antibody into the eye that can slow progression of the disease by blocking leaky blood vessels.



Miller, who helped pioneer the science behind Lucentis, approved by the Food and Drug Administration in 2006 as the first treatment for age-related macular degeneration, hopes to see a new generation of treatments emerging in the next five to 10 years.

Some of those new treatments could be less uncomfortable and time-consuming than today's injections. The emerging field of gene therapies, for instance, promises "one and done" procedures that could stop the disease in its tracks by inserting healthy genes into cells in place of defective or missing ones. Another approach involves stimulating cells in the retina to act as mini-production factories that generate proteins to protect the macular.

Such advances can't come soon enough for such patients as Laura Brennan, 64, of South Boston, who gets shots into her eyes every two months to stabilize her vision.

Brennan, who first experienced wavy vision when she was in her 50s, is determined to keep living her normal life. The injections and other adjustments have enabled her to continue walking, swimming, and working as a chef for Foodie's Markets in South Boston and the South End.

"When I first noticed that I couldn't make out someone's face across the room, that was very difficult," said Brennan, who recalls her father also developing macular degeneration late in life. "But I've been able to adapt. I know who people are by their steps or their voice. At this point, my goal is to preserve the vision that I have, not to have it decrease anymore."



Hemera Biosciences, a Waltham startup, is seeking to develop a kind of vaccine that would make treatments easier and less invasive for patients like Brennan.

"Patients in their 60s and 70s will go to their ophthalmologists," said Hemera chief executive Adam Rogers. "If they're diagnosed with AMD, they can receive a shot and keep it at bay during their lifetimes. I think that's something we could see in the next five to seven years."

Biopharma giants such as Genentech, Novartis, and Regeneron are also working on experimental medicines. So are a raft of biotech startups ranging from Cambridge's Gemini Therapeutics to Regenxbio in Rockville, Md.

For drug makers, the tens of millions of people with age-related macular degeneration are a potentially lucrative market. Sales of current medicines, mostly first-generation treatments including Lucentis, totaled nearly \$5 billion in 2016, and the expected new drugs will expand the market to \$11.5 billion by 2026, the British analytics firm GlobalData projects.

The approval of the first-ever gene therapy for any disease last December galvanized eye researchers. The new drug, Luxturna, treats a rare genetic

retinal disease in children by replacing a mutation with a corrective gene. In March, Mass Eye and Ear performed the first-ever procedure to administer the drug to a patient.

"It opened up the avenue for other gene-based treatments, and some of that might be applicable to AMD," said Miller.

While macular degeneration is thought to be influenced not only by genetics but by environmental factors,

such as smoking, "gene therapies have incredible potential" to treat the disease, said Luk Vandenberghe, cofounder of Odyia Therapeutics, a Boston nonprofit working to commercialize retinal disease research. Decades of research to understand diseases is now helping to power the new approaches to treatments, he said.

There's also hope that the success of gene therapies for maladies of the eye could help launch similar kinds of treatments for other diseases. Ben Shaberman, an official at the Foundation Fighting Blindness, a patient advocacy group, said the retina - a thin tissue lining the back of the eye - is emerging as an ideal proving ground for the young gene therapy field.

"The retina is accessible and a really good target," he said. "If you get things to work in the retina, there's a good chance you could apply them to neurodegenerative disorders of the brain or the central nervous system."



Gemini, based in Kendall Square, is trying to bring the precision medicine model being deployed in targeted cancer treatments to AMD. Unlike drug developers that try to make one-size-fits-all treatments for macular degeneration, it's focusing on treatments tailored to subsets of patients with distinct genetic variations that put them at risk.

"We believe that genetics plays a key role, and we're spending a lot of time trying to understand these subpopulations," said Gemini chief executive James McLaughlin.



Sometimes patients themselves aren't sure what role genetics has played in their disease. Teare, who was diagnosed with the disease in 2016, doesn't know anyone in his family with it. He wonders if his exposure to sunlight while boating or skiing was a factor.



Teare feels lucky to have the less severe form of the disease. And he's been quick to embrace lifestyle changes - eating a diet rich in fish and vegetables and wearing sunglasses with ultraviolet eye protection - in an effort to keep it from progressing. Last year, he ran the Marine Corps Marathon in Washington, D.C., to raise money for the Foundation Fighting Blindness. He's counting on his healthy diet and lifestyle - and his upbeat attitude - as he awaits the progress of research programs.

"This isn't a terminal illness," he said. "I feel I can make lifestyle changes that will keep it from progressing until there's some kind of treatment."

By Robert Weisman, Globe Staff September 09, 2018

# REMINDERS



## Membership Madness++

Hi Everyone! Becky from the office here. All chapters should have received their membership packages. Independent membership will be sent shortly.

Early Bird Draw – November 2, 2018

Chapter Rebate Deadline – December 7, 2018

All 2019 Memberships Due – December 28, 2018

White Cane Week Orders Due – January 4, 2019

WCW Insurance Requests Due – January 4, 2019

## DON'T FORGET DONATIONS!++

Donations Received in the office in 2018 are the only ones that can be receipted for 2018. Remember to send those donations if you want receipts.

[www.ccbnational.net](http://www.ccbnational.net)

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