

ocumel canada



AN INITIATIVE OF
save your skin
FOUNDATION

Ocumel Canada

2021 Annual Report

January – December 2021
End of Year Report on Ocumel Canada
Activity & Achievements
www.ocumelcanada.ca



About

Ocumel Canada, an initiative of Save Your Skin Foundation, was formed to increase awareness, advance treatment options, and build a supportive community for those diagnosed with primary and/or metastatic ocular melanoma (OM). Ocumel Canada is in close collaboration with a global Medical Advisory Board and partner patient representation organizations with the endeavour to build on international best practices to improve patient outcomes for Canadians touched by this disease.

We envision a future when ocular melanoma will be a treatable and manageable disease and where patients in Canada can easily find support and courage after diagnosis.

ocumelcanada@saveyourskin.ca

www.ocumelcanada.ca

Vision

We envision a future when ocular melanoma will be a treatable and manageable disease and where patients in Canada can easily find support and courage after diagnosis.

Mission

- Advocate for early detection of ocular melanoma
- Enable access to early treatment of primary ocular melanoma
- Work towards a consistent approach to treatment of metastatic ocular melanoma
- Integrate best practices from international collaboration
- Support patients who have been diagnosed with primary or metastatic ocular melanoma
- Build a network of support for patients and caregivers



Compassion for Patients and Caregivers



Passion for Promoting Access to Patient Care



Belief in Science



Devotion to Improving Ocular Melanoma Patient Outcomes

Conferences

- Attended 15th Annual Canadian Melanoma Conference (virtual)
- Attended Melanoma Research Alliance Scientific Retreat (virtual)
- Attended ASCO Congress (virtual sessions)
- Attended ESMO Congress (virtual sessions)
- Attended CureOM Global Science Meeting
- Attended Society for Melanoma Research Congress
- Attended CureOM Patient and Caregiver Symposium

The poster features a teal header with the text "EYES ON A CURE: Ocular Melanoma Patient and Caregiver Global Symposium Virtual Event". Below this is a dark blue bar with "Save the Date | November 19-20, 2021". The central graphic is a large "10" where the "0" is a circle, both filled with a grid of diverse people's faces. Below the "10" is the text "YEARS HOPE CHANGES EVERYTHING". At the bottom, there is a dark blue footer with the website "melanoma.org/event/cureomsymposium" and the MRF logo (Melanoma Research Foundation - Cure Ocular Melanoma).

EYES ON A CURE:
Ocular Melanoma Patient and
Caregiver Global Symposium
Virtual Event

Save the Date | November 19-20, 2021

10
YEARS HOPE CHANGES EVERYTHING

For more information, please visit:
melanoma.org/event/cureomsymposium

MRF MELANOMA RESEARCH FOUNDATION
CURE OCULAR MELANOMA

Meetings

- Held Ocular Melanoma Physician Task Force planning meetings
- Hosted Ocular Melanoma Task Force Canada meetings
- Attended/Co-Chaired international Ocular Melanoma coalition meetings
- Attended meetings with CureOM re: Global Vision Registry
- Held calls with Physicians and pharmaceutical partners to discuss issues in ocular melanoma patient special access to treatment
- Hosted Melanoma/NMSC/OM Patient/Caregiver Roundtable
- Coordinated meetings with Alberta Association of Optometrists & BC Doctors of Optometry for collaboration on #EyeGetDilated campaign
- Presented Ocumel Canada to MI-PAC group, AIM at Melanoma
- Attended CureOM “Ask the Expert” Presentation with Dr. Ezekiel Weis

Join Us in Building the
Ocular Melanoma Physician Task Force: *Ocular Melanoma Care Pathways Across Canada*
13 May 2021 | 2pm PT / 3pm MT / 5pm ET

Virtual Meeting link/dial-in will be provided

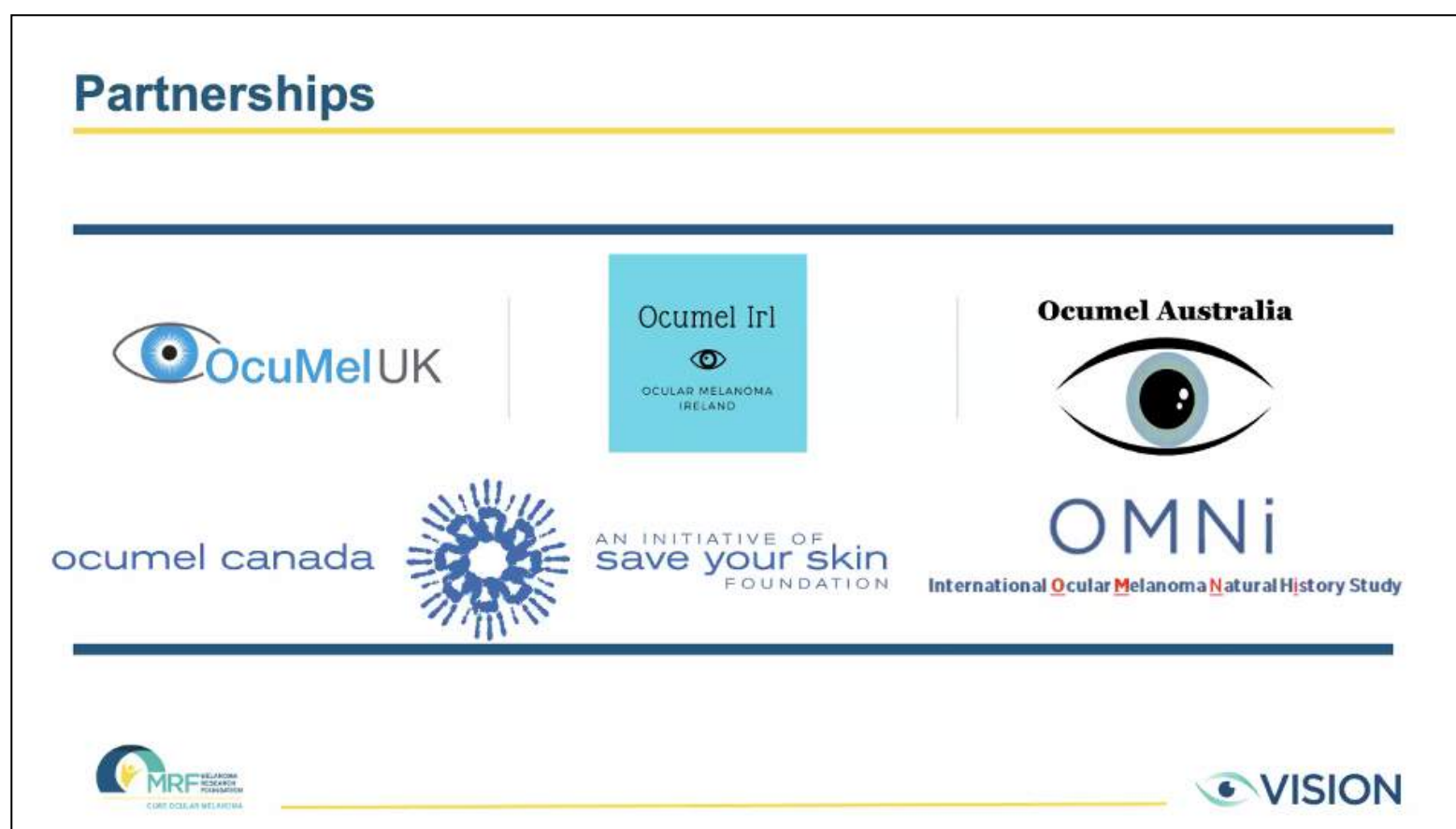
Discussion Points on Primary and Metastatic Ocular Melanoma:

- Referral Pathways
- Genetic Testing
- Access to Treatment and/or Clinical Trials
- Guidelines and Surveillance
- Coordinating our Approach

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Education & Awareness


- Collaborated with MI-PAC, MRF Global Coalition for Melanoma Patient Advocacy, and Ocumel UK on Melanoma Month campaigns
- Hosted Webinar: Post-ASCO 2021 with Dr. Hamid
- Released Ocumel Canada Report: Updating the Ocular Melanoma Care Landscape in Canada
- Published blog posts:
 - “Ocumel Canada News!” in English and French
 - “Continuing Ocular Melanoma Awareness All Year Round” in English and French
- Deployed newsletter:
 - "Ocular Melanoma Awareness"




Education & Awareness

- Ran digital #EyeGetDilated campaign for Ocular Melanoma Awareness

#EYEGETDILATED





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LEANNE, EDMONTON, AB

"CANCER. The word strikes fear into the hearts of millions, but most people have never heard of eye cancer. I certainly had not, until January 30, 2017. Around that time, I had started to notice white "flashes" in my left eye. I decided to visit my optometrist to get his advice. At my appointment, he noticed something of concern and referred me to a retina specialist the following week. My eyes were thoroughly examined, including a dilated eye exam, and at the end of a long visit, the ophthalmologist sat me down and told me that there was a melanoma tumour in my eye – I had cancer.

I was referred to an ocular oncologist and a flurry of activity ensued. Just five weeks later, I had brachytherapy treatment, which involved a radiated "plaque" being surgically attached to my eye at the tumour site for five days. The treatment was successful, and over time, the tumour has shrunk and died. As a result of the radiation, I have lost clear vision in my eye, but I am grateful that my eye could be preserved.

Ocular melanoma is a rare and dangerous cancer. Even with successful brachytherapy treatment, more than 50% of patients have metastasis. If this happens, there is no effective treatment available. The risk of metastasis is lower for smaller tumours, so early detection is very important.

Nearly four years after my diagnosis, I am profoundly grateful that I have remained healthy. I've made it my mission to raise awareness about the importance of eye health. I urge everyone to get a regular dilated eye exam and to pay attention to any changes in vision. Your life could depend on it."

MISSING A CHECK?

Ask your Optometrist about the importance of early detection of Ocular Melanoma

optometrists.ab.ca

Alberta Association of Optometrists

- Doctor
- Dentist
- Dermatologist
- Dilated Eye Exam


For more information contact ocumelcanada@saveyourskin.ca | 1-800-460-5832

Ocular melanoma (OM) is the most common form of eye cancer in adults.


A dilated eye exam is the best way to detect it.

Schedule yours today.

#EYEGETDILATED

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LA FONDATION sauve ta peau

#EXAMEN DU FOND D'OEIL

"J'encourage tout le monde à se faire faire un examen annuel de la vue comprenant un examen du fond d'oeil et à ne jamais ignorer les changements de vision. Votre vie pourrait en dépendre."

~ Leanne, Edmonton, ALB.


IL VOUS MANQUE UN CROCHET?


Demandez à votre optométriste au sujet de l'importance de la détection précoce du mélanome oculaire.

bc.doctorsofoptometry.ca

- Médecin
- Dentiste
- Dermatologue
- Examen du fond d'oeil

EXAMEN DU FOND D'OEIL





LA FONDATION sauve ta peau

SHEILA, Victoria, C.-B.

« Je porte des lunettes depuis mon adolescence et, habituellement, je vais chez l'optométriste au moins tous les deux ans. Au début de la cinquantaine, la vie a pris le dessus sur moi (comme c'est le cas pour beaucoup d'entre nous) et j'ai eu un retard de plus d'un an sur mes rendez-vous réguliers. Une nuit, alors que j'étais au lit et que tout était calme, j'ai remarqué des lumières clignotantes dans ma vision périphérique. J'ai l'oeil gauche endormi depuis l'enfance et je n'étais pas capable de discerner de quel oeil provenait le clignotement. Sachant que c'était inhabituel et que j'étais en retard dans mes rendez-vous habituels, j'ai pris rendez-vous chez l'optométriste, qui a effectué l'examen complet habituel, y compris la dilatation des yeux. On a repéré quelque chose derrière mon oeil et on m'a orienté vers un médecin ophtalmologue. Je suis allé le voir et on m'a fait passer plusieurs scans de l'oeil.

Plusieurs jours plus tard, on m'a envoyé à l'hôpital pour que le médecin me fasse passer une échographie de l'oeil. C'est là que j'ai appris que j'avais une tumeur à l'oeil gauche et j'ai été rapidement envoyé chez un oncologue spécialisé dans le mélanome oculaire. Qui savait que cela existait ? Moi, je ne le savais pas !

Trois semaines plus tard, je recevais plusieurs photos, des scans et une autre échographie de mon oeil gauche. C'était au printemps 2019. L'oeil a été surveillé tous les 3 mois par l'oncologue jusqu'en novembre où un certain changement avec la tumeur a été identifié.

À la mi-décembre 2019, j'ai été traitée par curiethérapie (où un capuchon en or contenant des graines de radiation a été chirurgicalement fixé à mon oeil, la radiation étant précisément dirigée vers la tumeur). Ce « capuchon » a été porté sur l'oeil pendant 1 semaine et retiré chirurgicalement ensuite. Des gouttes ophtalmiques ont été utilisées plusieurs fois par jour pour réduire le risque d'infection et l'enflure. Un pansement/protecteur oculaire a également été mis en place afin que mon oeil ne soit pas heurté par inadvertance pendant le traitement.

Six mois plus tard, je suis revenu pour un suivi et j'ai constaté que la tumeur avait diminué. C'était une bonne nouvelle. Plusieurs mois plus tard, lors du suivi suivant, la tumeur avait encore diminué ! Je continue mes rendez-vous tous les six mois pour m'assurer que les choses évoluent dans la bonne direction. Jusqu'à présent, par mesure de précaution, j'ai passé une échographie et une IRM pour vérifier l'absence de métastases dans mon foie.

Je suis très chanceuse que cela se produise dans mon oeil qui a déjà une vision imparfaite. C'est une chance inouïe. Il s'agit d'un type de cancer tellement unique et j'encourage tout le monde à se faire examiner les yeux, y compris par dilatation, surtout s'il y a eu le moindre changement dans votre vision. »

IL VOUS MANQUE UN CROCHET?

Demandez à votre optométriste au sujet de l'importance de la détection précoce du mélanome oculaire.

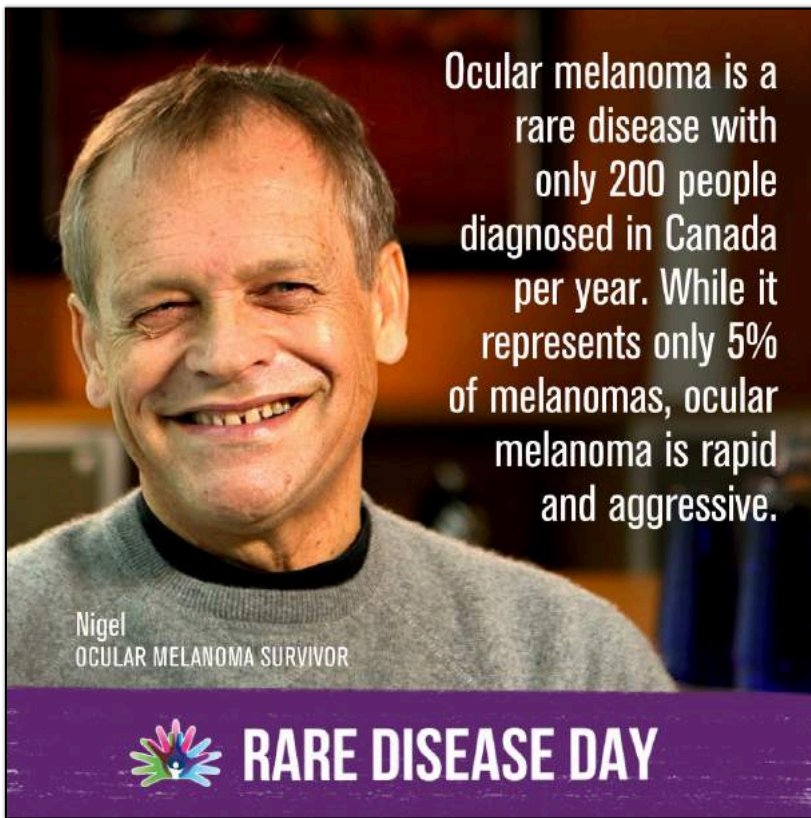
bc.doctorsofoptometry.ca

- Médecin
- Dentiste
- Dermatologue
- Examen du fond d'oeil

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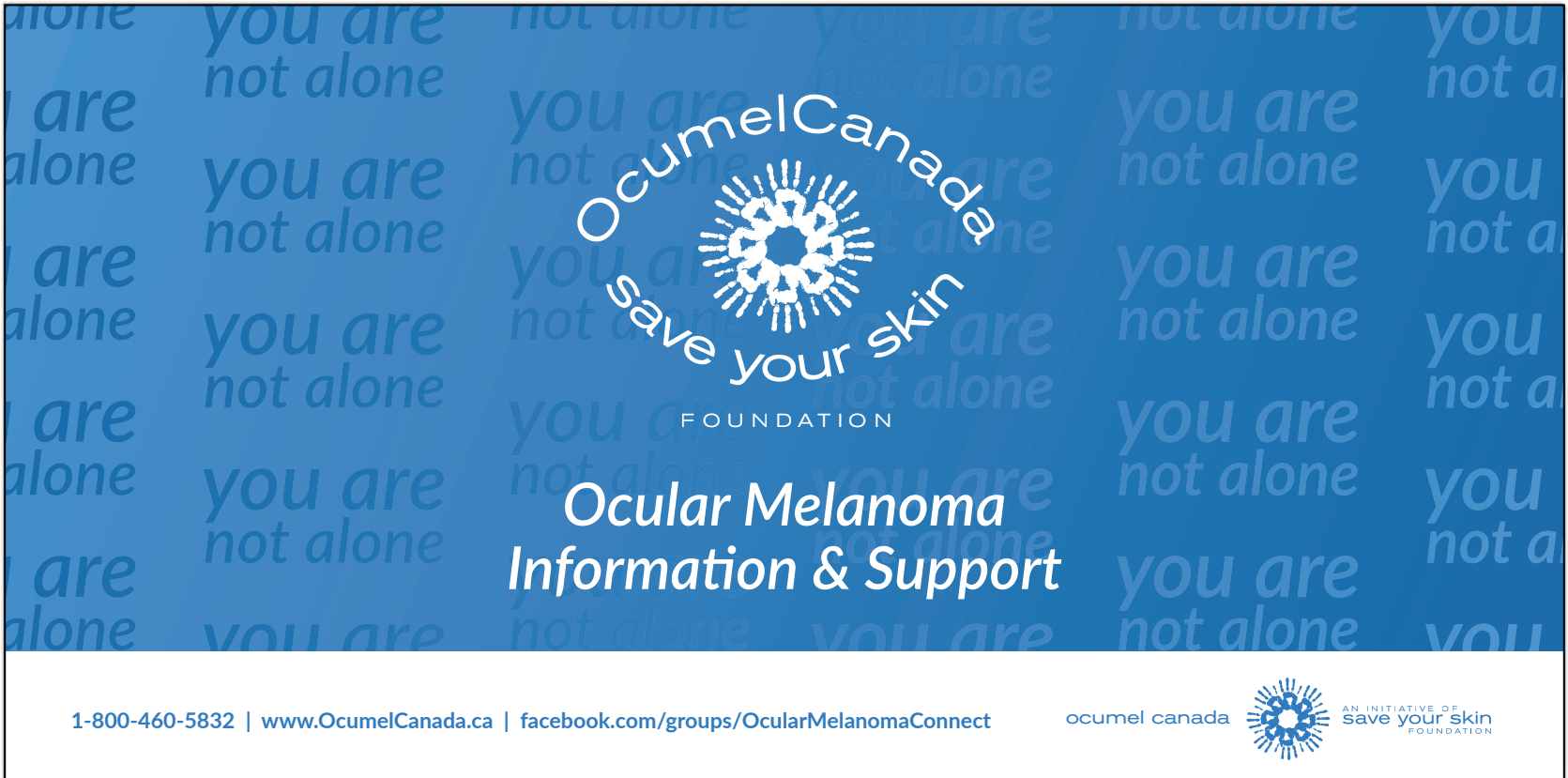
Education & Awareness

- Ran Rare Disease Day and World Sight Day posts highlighting Ocular Melanoma
- Ran iPatchFor campaign posts



Marketing & Events

- Created new banners for Ocumel Canada (French & English)



Marketing & Events

- Created Team Ocumel Canada strategy for Move for Melanoma
- Created team building and wrap videos for Team Ocumel Canada



A promotional poster for "MOVE FOR MELANOMA". The text reads: "MOVE FOR MELANOMA" in large orange letters, "OCULAR MELANOMA & NON-MELANOMA SKIN CANCERS" in blue, "ACROSS CANADA" with a green checkmark, and "SEPT. 25-26, 2021". Below this is a paragraph: "This September, join us from your living room, your yard, your neighbourhood park, or your favorite trail to move your body, raise funds for skin cancer and ocular melanoma patients and celebrate survivors." A call to action box says: "VISIT SAVEYOURSKIN.CA TO LEARN MORE AND GET MOVING! OR CONTACT US AT MARIANNE@SAVEYOURSKIN.CA". At the bottom are logos for "ocumel canada" and "AN INITIATIVE OF save your skin FOUNDATION".

A video player showing a man, Nigel Deacon, in front of a world map. The video title is "Nigel Deacon Ocular Melanoma Survivor". The "MOVE FOR MELANOMA" logo and event details are visible in the top right corner of the video frame.

A screenshot of a Facebook post from "Ocumel Canada" dated "14 September 2021". The text says: "Join us Sept 25-26th to support Move for Melanoma - a cross-Canada activity challenge to bring awareness to skin cancers and ocular melanoma, and to raise funds for patients affected by these illnesses. Join Team Ocumel Canada! Click here to join the team, sponsor or donate, share with your friends and family, and help us help others: https://saveyourskin.akaraisin.com/.../t/TeamOcumelCanada". At the bottom is a banner with the "MOVE FOR MELANOMA" logo and the text: "Help us fundraise for Ocular Melanoma Patients! Click here to join Move for Melanoma! September 25-26, 2021 across Canada".

A video player showing the same three people with bicycles as in the first image. The video title is "Team The Eyes Have It" and the location is "Victoria, BC".

Earned Media



CANCER SURVIVOR READYING FOR SECOND MARATHON FUNDRAISER, CHEK News, Sept 23, 2021



FAMILY TEAM TO THROW AXES FOR SIX HOURS TO SUPPORT MEMBER AND OTHER PATIENTS BATTLING CANCER, Campbell River Mirror, Sept 17, 2021.



THEZOOMER ON IMMUNOTHERAPY, The Zoomer, Jan 26, 2021.



EMPOWERING CANCER PATIENTS TO SELF ADVOCATE, Zoomer Radio February 11 2021.



PATIENT GROUPS WANT FUNDING TO EASE DEADLY CANCER BACKLOG, Healthing.ca, March 10, 2021.



CSA MEMBER PROFILE: LOUISE BINDER, SAVE YOUR SKIN FOUNDATION, BioCanRX, July 5, 2021.

Ocular Melanoma Connect Connexion Mélanome Oculaire



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Ocular Melanoma Connect/Connexion mélanome oculaire

Private group · 114 members





30%

Growth in 2021

Patient Community

- Continued outreach and support of Canadian patients and caregivers touched by ocular melanoma

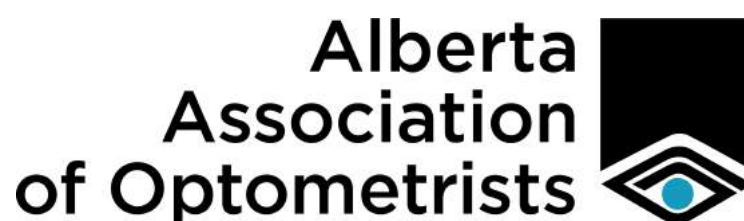
	<h2>You are not alone</h2>
<h3>Ocular Melanoma (OM)</h3>	<h3>Ocumel Canada</h3>
<p>OM is rare, affecting approximately five in a million people; about 200 cases are diagnosed per year in Canada. Like other melanomas, it begins in melanocytes – the cells that produce the pigment melanin. Also referred to as uveal melanoma, 90% of primary OM develops in the choroid.</p> <p>Uveal Melanoma - The uvea is a three-layered part of the eye. It is made up of the choroid, iris and ciliary body. Uveal melanoma can form in any of these layers and is named for where it forms:</p> <ul style="list-style-type: none"> • Choroidal melanoma • Iris melanoma • Ciliary melanoma • Conjunctival Melanoma <p>For more info, watch our webinar: www.bit.ly/OcumelWeb</p>	<p>Ocumel Canada, an initiative of Save Your Skin Foundation, was founded in 2019 in order to help those diagnosed with OM find the latest information about the disease and a supportive community for patients and caregivers. If you or someone you know has been touched by this rare cancer and is in need of assistance, please reach out to us.</p> <p>Visit OcumelCanada.ca to find up-to-date educational and support resources from Canada, the United States, and around the world. Or join our support group on Facebook here: Fb.com/groups/OcularMelanomaConnect</p>
	<p>Ocumel Canada 1-800-460-5832 ocumelcanada@saveyourskin.ca</p>

	<h2>Vous n'êtes pas seul</h2>
<h3>Mélanome Oculaire (MO)</h3>	<h3>Ocumel Canada</h3>
<p>Le mélanome oculaire est rare et touche environ cinq personnes sur un million ; environ 200 cas sont diagnostiqués chaque année au Canada. Comme d'autres mélanomes, il commence dans les mélanocytes - les cellules qui produisent la mélanine pigmentaire. Également appelé mélanome uvéal, 90 % des MO primaires se développent dans la choroïde.</p> <p>Mélanome uvéal - L'uvée est une partie de l'œil à trois couches. Elle est composée de la choroïde, de l'iris et du corps ciliaire. Le mélanome uvéal peut se former dans n'importe laquelle de ces couches et est nommé d'après l'endroit où il se forme :</p> <ul style="list-style-type: none"> • Mélanome choroïde • Mélanome de l'iris • Mélanome ciliaire • Mélanome conjonctival 	<p>Ocumel Canada, une initiative de la Fondation Sauve ta peau, a été fondée en 2019 afin d'aider les personnes diagnostiquées d'un MO à trouver les dernières informations sur la maladie et une communauté de soutien pour les patients et les soignants. Si vous ou quelqu'un que vous connaissez avez été touché par ce cancer rare et avez besoin d'aide, n'hésitez pas à nous contacter.</p> <p>Visitez le site: SauveTaPeau.ca/OcumelCanada pour trouver des ressources éducatives et de soutien actuelles provenant du Canada, des États-Unis et du monde entier. Ou joignez-vous à notre groupe de soutien sur Facebook ici: Fb.com/groups/OcularMelanomaConnect</p>
	<p>Ocumel Canada 1-800-460-5832 ocumelcanada@saveyourskin.ca</p>

Thank you to our Supporting Partners and Collaborators



IMMUNOCORE



Ocular Melanoma Task Force Canada (OMTFC)