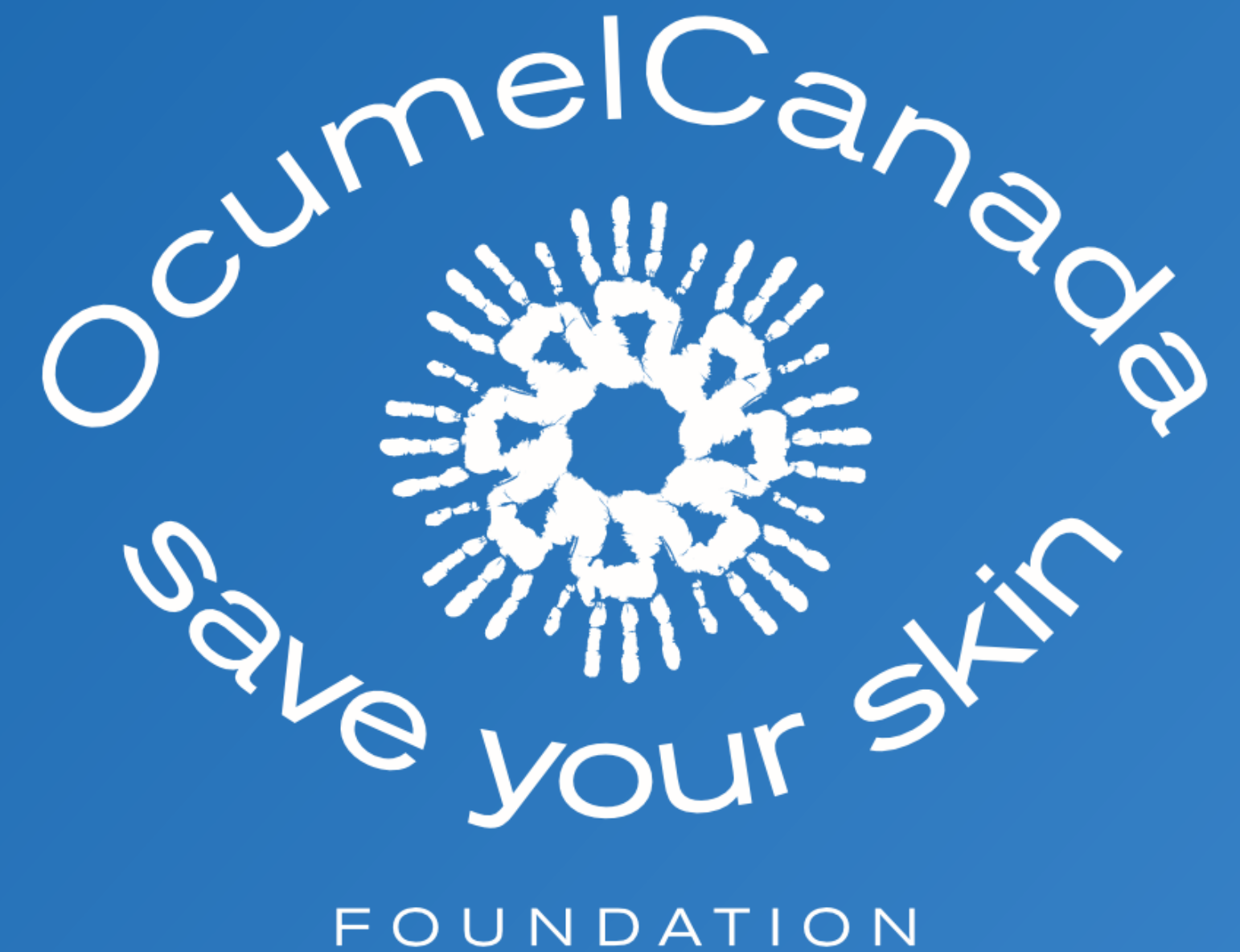


# Ocumel Canada

2018-2020 Report



January 2018 - December 2020

Report on Ocumel Canada Activities & Communications

[www.ocumelcanada.ca](http://www.ocumelcanada.ca)

# About Ocumel Canada

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.

## Our 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

# Core Values



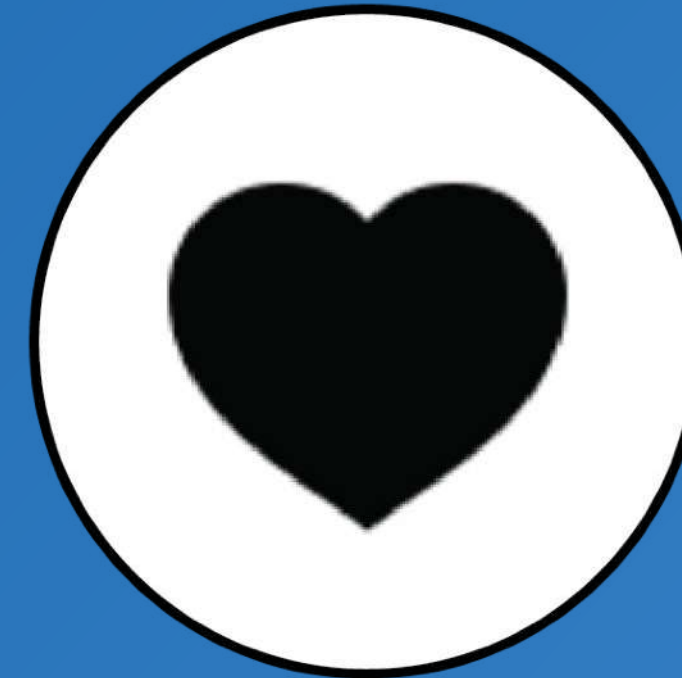
Compassion for  
Patients and Caregivers



Belief in Science



Passion for Promoting  
Access to Patient Care



Devotion to Improving  
Ocular Melanoma  
Patient Outcomes

# Monthly Highlights



# 2018 Monthly Highlights

## January

- Publication of blog post titled: Opening Our Eyes to Ocular Melanoma, written by Nigel Deacon
- Created patient survey and 2018 strategy for building ocular melanoma patient support

## February

- Launched Patient Survey on Ocular Melanoma in English and French

## April

- Attended the 7th Annual Eyes on a Cure: Ocular Melanoma Patient and Caregiver Symposium, Aurora, Colorado, USA

## July

- Began Ocular Melanoma survey analysis and reporting

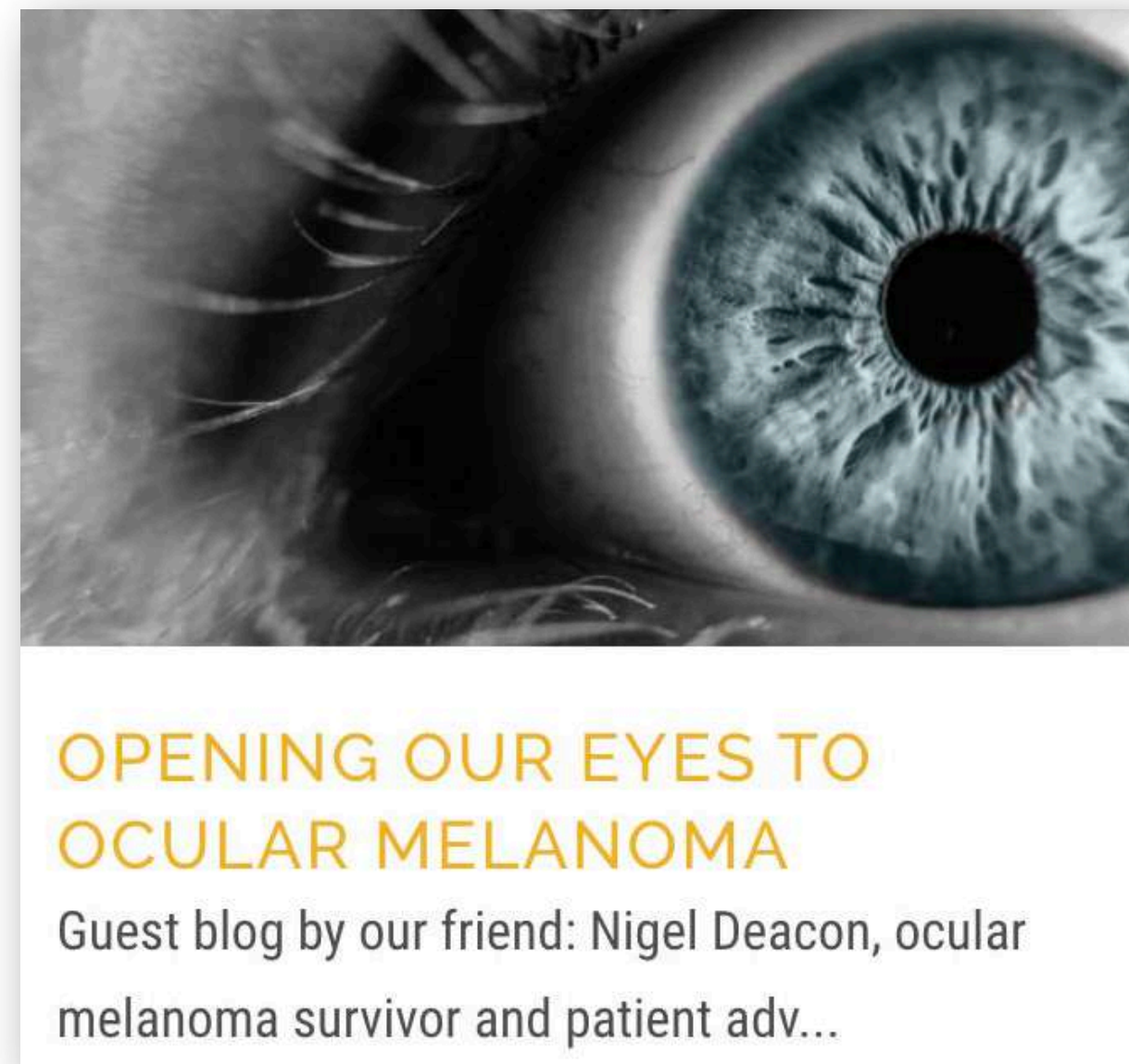
## October

- Created logo and visual identity for Ocumel Canada

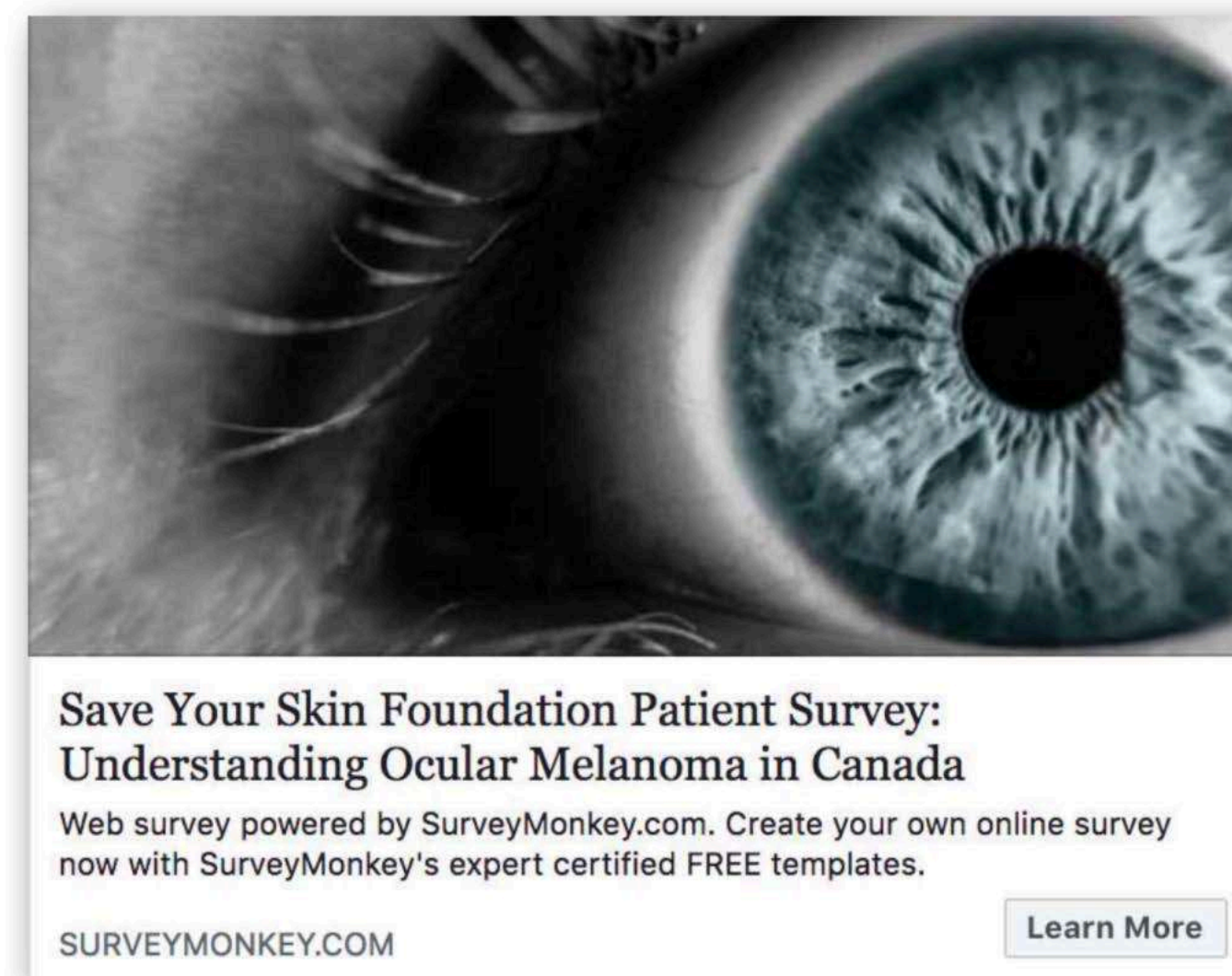
## December

- Created [OcumelCanada.ca](http://OcumelCanada.ca) online presence

# 2018 Highlights



Published blog post in French and English



Launched survey



Published survey results

# 2018 Highlights

**Save Your Skin Foundation**  
Published by Natalie Richardson · 19 December 2018 ·

Here are 5 quick facts on ocular melanoma:

1. Eye melanoma is often deadly.
2. Melanoma can occur without symptoms so you may not know that you even have a problem.
3. Your environment and what you eat, breathe, smoke, drink, or do is not related to the development of eye melanoma.
4. Eye melanoma can be cured if caught early enough and if it does not show genetic mutation.
5. Be smart, beat it.



**"Get your eyes dilated once a year for life."**  
- Carol L. Shields, MD



MELANOMA.ORG  
**#EyeGetDilated: Be Smart. Beat It.**  
Guest blog post by Carol L. Shields, MD: Ocular melanoma is a ser...



Created Ocumel Canada visual identity and online presence



# 2019 Highlights

## January

- Officially launched Ocumel Canada initiative
- Drafted and distributed Ocumel Canada press release on Canadian news wire
- Earned 17 full-text postings of Ocumel Canada release to news sites and blogs with estimated total audience of 150,000+

## February

- Hosted Webinar: Ocular Melanoma, Innovative Treatments and Beyond

## April

- Presented Ocumel Canada at Eyes on a Cure Symposium, CureOM, MRF, Raleigh NC, US

## August

- Launched health care professionals survey on Ocular Melanoma care pathways in Canada

## September

- Raised over \$3,000 for Ocular Melanoma patients during Move for Melanoma 2019

## November

- Participated in the CureOM #EyeGetDilated campaign
- Attended the 2019 CureOM Science Meeting at the Society for Melanoma Research Congress 2019

# 2019 Highlights

 **Save Your Skin Foundation**  
Published by Amy Rosvold · 15 January 2019 · 🌐

We are very excited to announce the launch of Ocumel Canada, a new initiative of Save Your Skin Foundation. Ocumel Canada will support patients, improve care pathways and create hope.

Learn more at [ocumelcanada.ca](http://ocumelcanada.ca)

 **Save Your Skin Foundation**  
Published by Amy Rosvold · 15 January 2019 · 🌐


We are very excited to announce the launch of Ocumel Canada, a new initiative of Save Your Skin Foundation.

Ocumel Canada is dedicated to increasing awareness of ocular melanoma, improving patient care, and creating hope for ocular melanoma patients.


Learn more at [ocumelcanada.ca](http://ocumelcanada.ca)



[ocumel canada](http://ocumelcanada.ca)  AN INITIATIVE OF **save your skin** FOUNDATION


 **Save Your Skin Foundation**  
15 January 2019 · Instagram · 🌐

We are very excited to announce the launch of Ocumel Canada!  
Learn more at [ocumelcanada.ca](http://ocumelcanada.ca)





0:05 / 0:46

Announced the launch of Ocumel Canada

 **Save Your Skin Foundation**  
Published by Amy Rosvold · 16 January 2019 · 🌐

Read our latest press release!



[ocumel canada](http://ocumelcanada.ca)  AN INITIATIVE OF **save your skin** FOUNDATION

NEWSWIRE.CA  
**Launch of Ocumel Canada Offers New Hope for Canadians Diagnosed With Rare Ocular Melanoma**

Published Press Release in French and English

# 2019 Highlights

Published resources and Strategic Plan on the Ocumel website

Introducing Ocumel Canada, a new initiative of Save Your Skin Foundation



Learn more at [OcumelCanada.ca](http://OcumelCanada.ca)

## Ocular Melanoma Fact Sheet

There is an urgent need to increase awareness and improve the diagnosis of ocular melanoma.

## Questions to Ask Your Doctor - Primary Disease

Informed and Empowered Ocular Melanoma Patients Live Longer, Better Lives.

**There are a few specialists you may encounter, and you should know the difference between those specialists when choosing which will be best suited for your treatment plan.**

**Primary Eye Tumour Related Questions:**

- What is ocular melanoma and how does it differ from cutaneous (skin) melanoma?
- What are the dimensions of the tumour? Diameter? Height? Thickness? What do they mean for treatment options?
- Can I receive a written report with this information?

**Treatment Questions:**

- What are my treatment options and what are the differences? Are there different options or treatment centres that I should know about?
- Which treatment do you think is best for me and why?
- What type of radiation treatments do you offer?
- Do I need to have my eye removed?
- How many OM patients have you treated?
- Are there different outcomes depending on the different treatments?



### Our 2018/2019 Strategic Plan

**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
- Support patients who have been diagnosed with primary or metastatic ocular melanoma
- Build a network of support for patients and caregivers

### Our core values

-  Compassion for Patients and Caregivers
-  Passion for Promoting Access to Patient Care
-  Belief in Science
-  Devotion to Improving Ocular Melanoma Patient Outcomes

Ocumel Canada  
319, 3600 Windcrest Drive  
North Vancouver, BC V7G 2S5  
Canada  
[ocumelcanada.ca](http://ocumelcanada.ca)

ocumel canada  AN INITIATIVE OF **save your skin** FOUNDATION

# 2019 Highlights



**Ocular Melanoma:  
Innovative Treatments and Beyond**

*with presenters*

Nigel Deacon, Ocular Melanoma Survivor/Patient, British Columbia, Canada  
Dr. Marcus Butler, Princess Margaret Cancer Centre, Toronto, Ontario, Canada  
Dr. Omid Hamid, The Angeles Clinic and Research Institute, California, USA  
@OmidHamidMD ohamid@theangelesclinic.org

Friday, February 15, 2019 at 7am PST / 10am EST

This webinar will provide an update on the landscape of metastatic ocular melanoma treatment in Canada and the United States. Dr. Hamid and Dr. Butler will share their knowledge of current practices and care pathways, identifying the most pressing needs for patients. They will also discuss innovative treatment options such as IMCgp100, as well as clinical trials available to Canadian patients with ocular or uveal melanoma. Nigel Deacon will share his experience with this rare cancer; Kathy Barnard will facilitate the discussion.

OcumelCanada.ca ocumel canada save your skin FOUNDATION

**SYSF WEBINAR: OCULAR MELANOMA**

Ocular Melanoma – Innovative Treatments and Beyond With Presenters: Dr. Ma...

29 January, 2019

Hosted a webinar on Ocular Melanoma



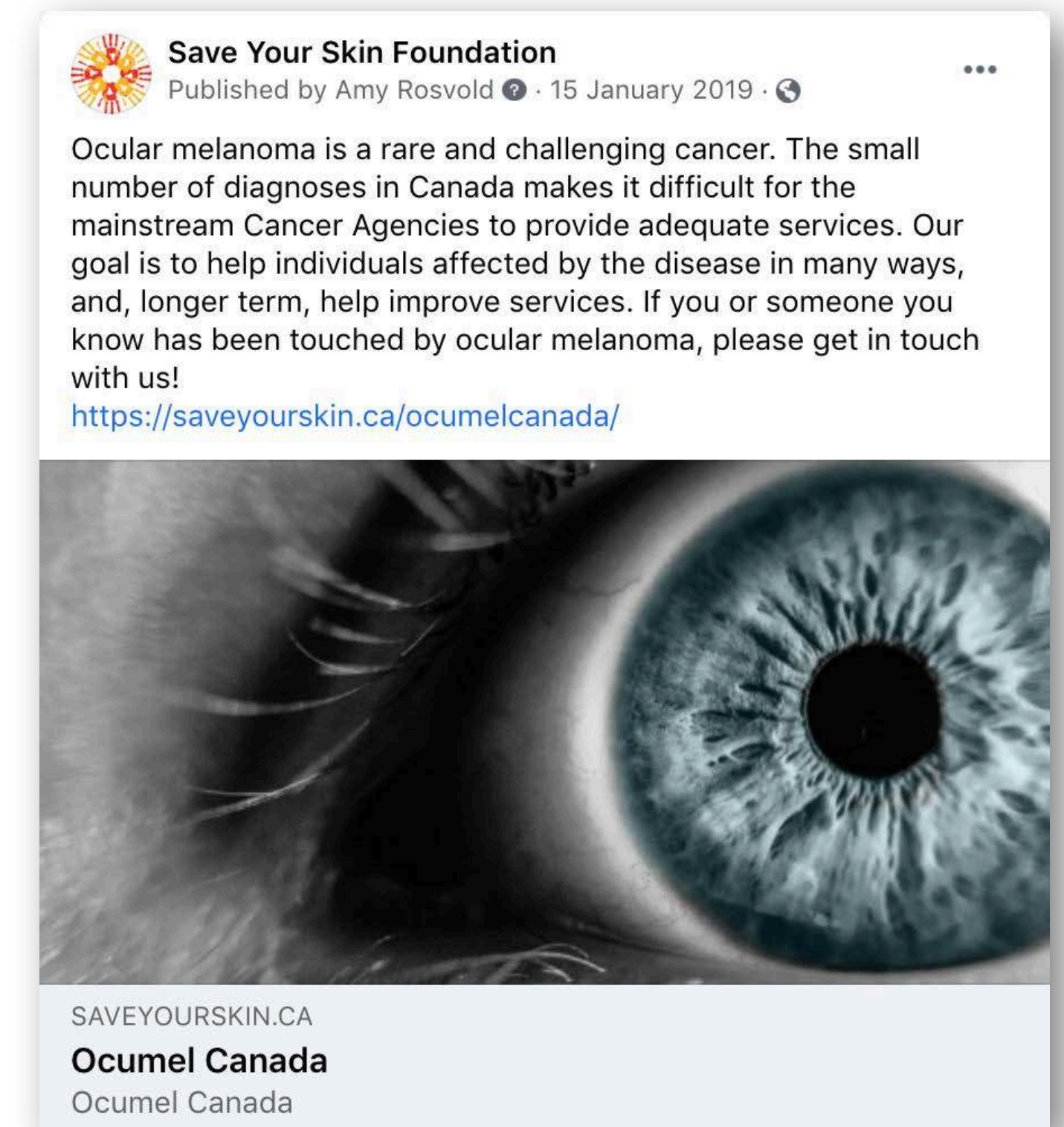
**Save Your Skin Foundation**  
Published by Amy Rosvold · 11 April 2019 ·

Next month we'll be participating in Ocumel UK's iPatchFor Campaign to raise awareness of the importance of regular eye examinations.  
Learn more at <http://www.ipatchfor.com/>




IPATCHFOR.COM  
**iPatchFor – Ocular Melanoma Campaign**  
ABOUT "I PATCH FOR" It is no exaggeration to say having regul...

Participated in the Ocumel UK's iPatchFor Campaign



**Save Your Skin Foundation**  
Published by Amy Rosvold · 15 January 2019 ·

Ocular melanoma is a rare and challenging cancer. The small number of diagnoses in Canada makes it difficult for the mainstream Cancer Agencies to provide adequate services. Our goal is to help individuals affected by the disease in many ways, and, longer term, help improve services. If you or someone you know has been touched by ocular melanoma, please get in touch with us!  
<https://saveyourskin.ca/ocumelcanada/>




SAVEYOURSKIN.CA  
**Ocumel Canada**  
Ocumel Canada

Promoted OC on Social Media

# 2019 Highlights

Introducing  
Ocumel Canada

ocumel canada  AN INITIATIVE OF  
save your skin  
FOUNDATION

**INTRODUCING: OCUMEL CANADA**

For the past year, Save Your Skin Foundation has been working with ocular melano...

15 January, 2019

Think uveal melanoma Uveal melanoma Presentation Symptoms Management Resources

When you see uveal melanoma, you can't afford to wait

Watch full video

**INTRODUCING THINK UVEAL MELANOMA, BY IMMUNOCORE**

We are happy to share with you the launch of chapter 1 of a new Uveal Melanoma D...

12 June, 2019

**#EYEGETDILATED**

- Doctor
- Dentist
- Dermatologist
- Dilated Eye Exam

**MISSING A CHECK?**  
Ask your Ophthalmologist about the importance of early detection of Ocular Melanoma

**#EYEGETDILATED – AWARENESS CAMPAIGN FOR OCULAR MELANOMA – NOVEMBER 2019**

The 4th annual #EyeGetDilated campaign kicks off November 1st! Throughout the mo...

04 November, 2019

Published several blog posts

# 2019 Highlights

 **Save Your Skin Foundation**  
Published by Natalie Richardson · 7 April 2019

It is with deep gratitude we attended this weekend's Eyes on a Cure Symposium, an informative and supportive event in so many ways. Thanks to CureOM and all participants for the warm welcome to Ocumel Canada!



18:52 / 47:44

**CURE Ocular Melanoma was live.**  
6 April 2019

*A Community of Partners*



**Research Collaborations**  
Auburn University  
Columbia University  
Duke University  
State of North Carolina  
Thomas Jefferson University  
University of Alabama at Birmingham  
University of North Carolina

**Social/Emotional Support**  
Duke University  
Thomas Jefferson University  
University of North Carolina

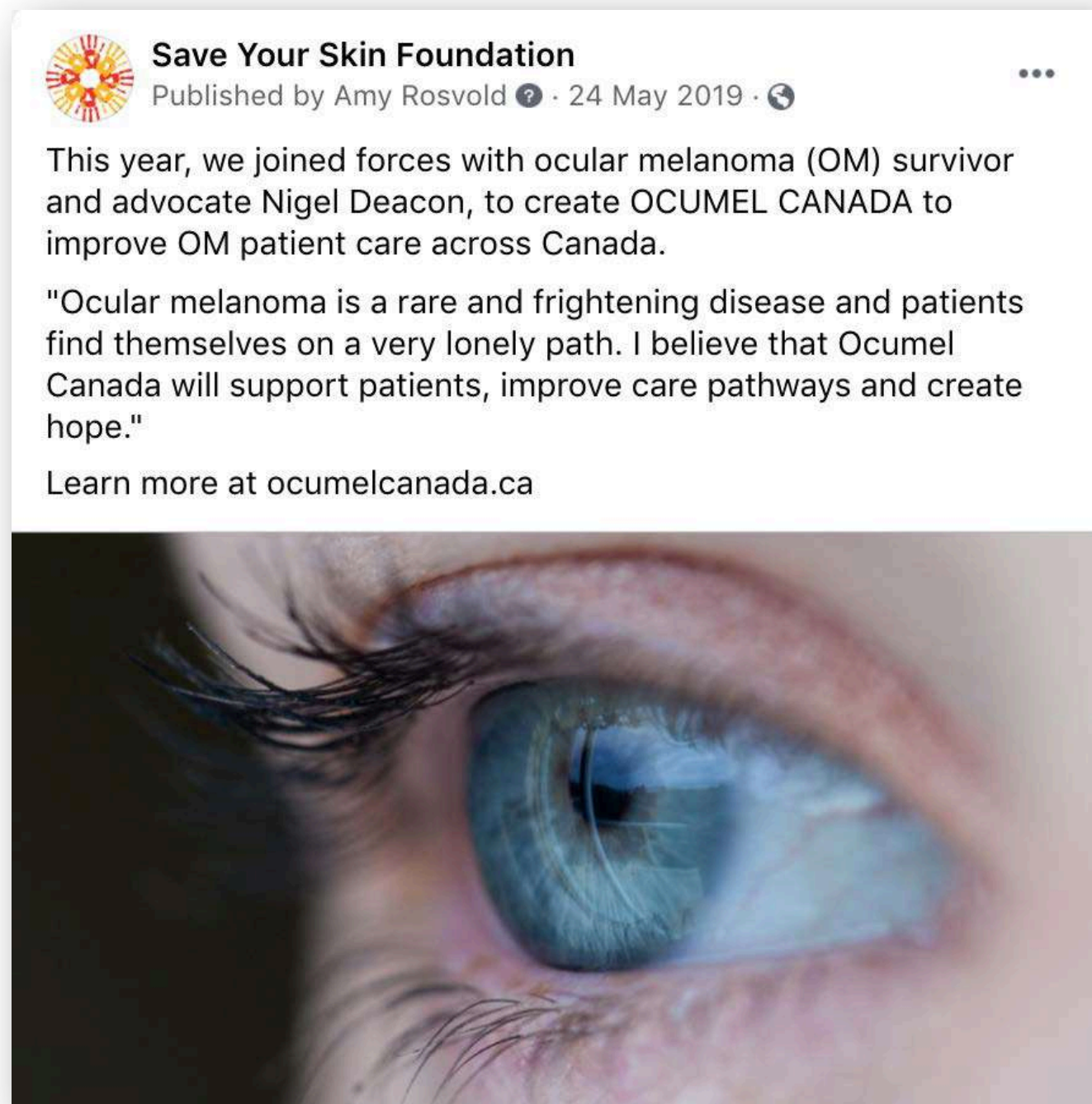
**Historic Attendance**  
Over 130 ocular melanoma patients, caregivers, researchers and physicians attended the 2019 CURE OM Symposium

**International Partnerships**  
OM advocacy groups representing 4 nations exploring global collaboration opportunities

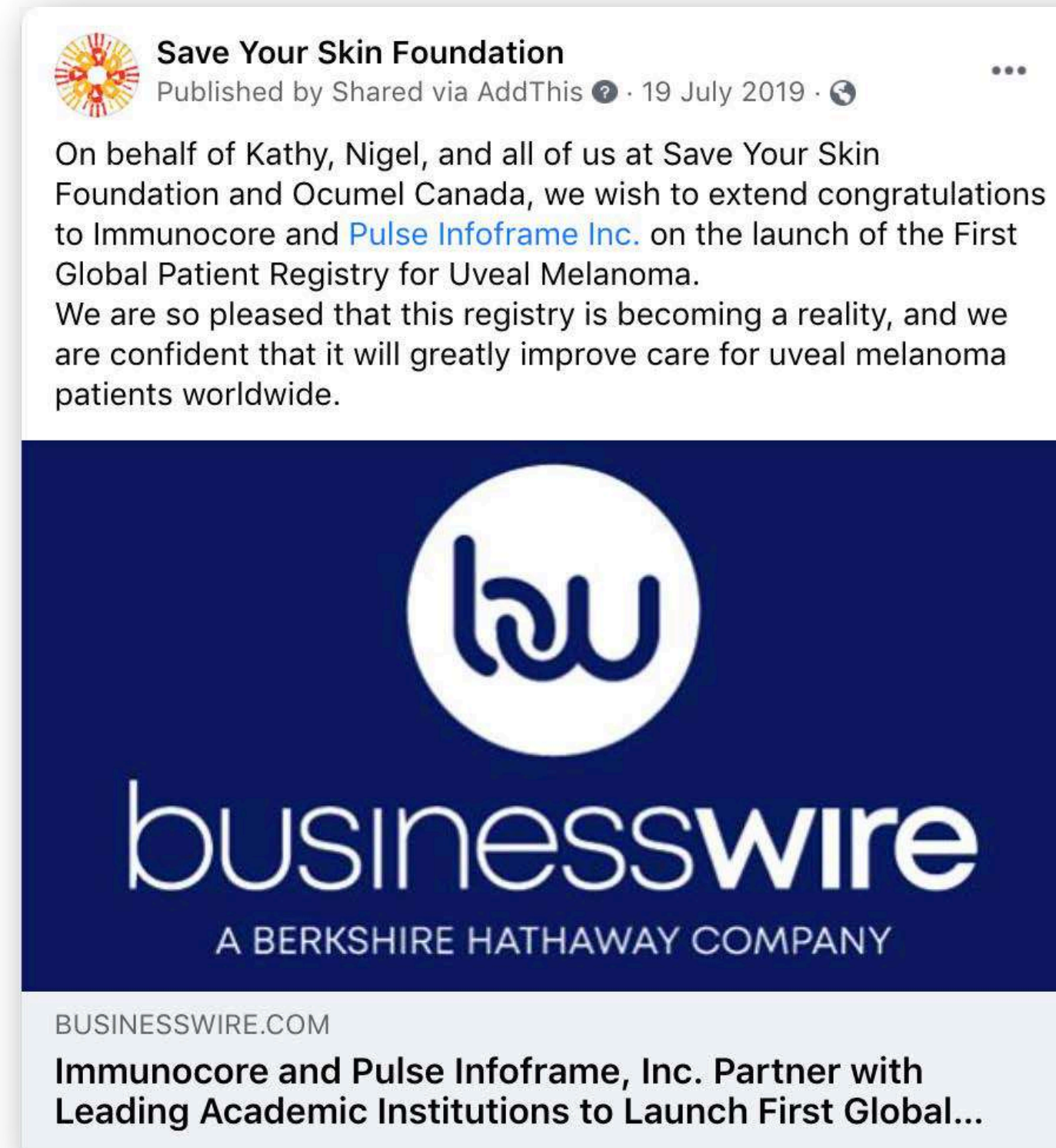
**Unique Populations**  
Welcoming the ocular melanoma communities of Huntersville, NC and Auburn, AL

Attended the Eyes on a Cure Symposium

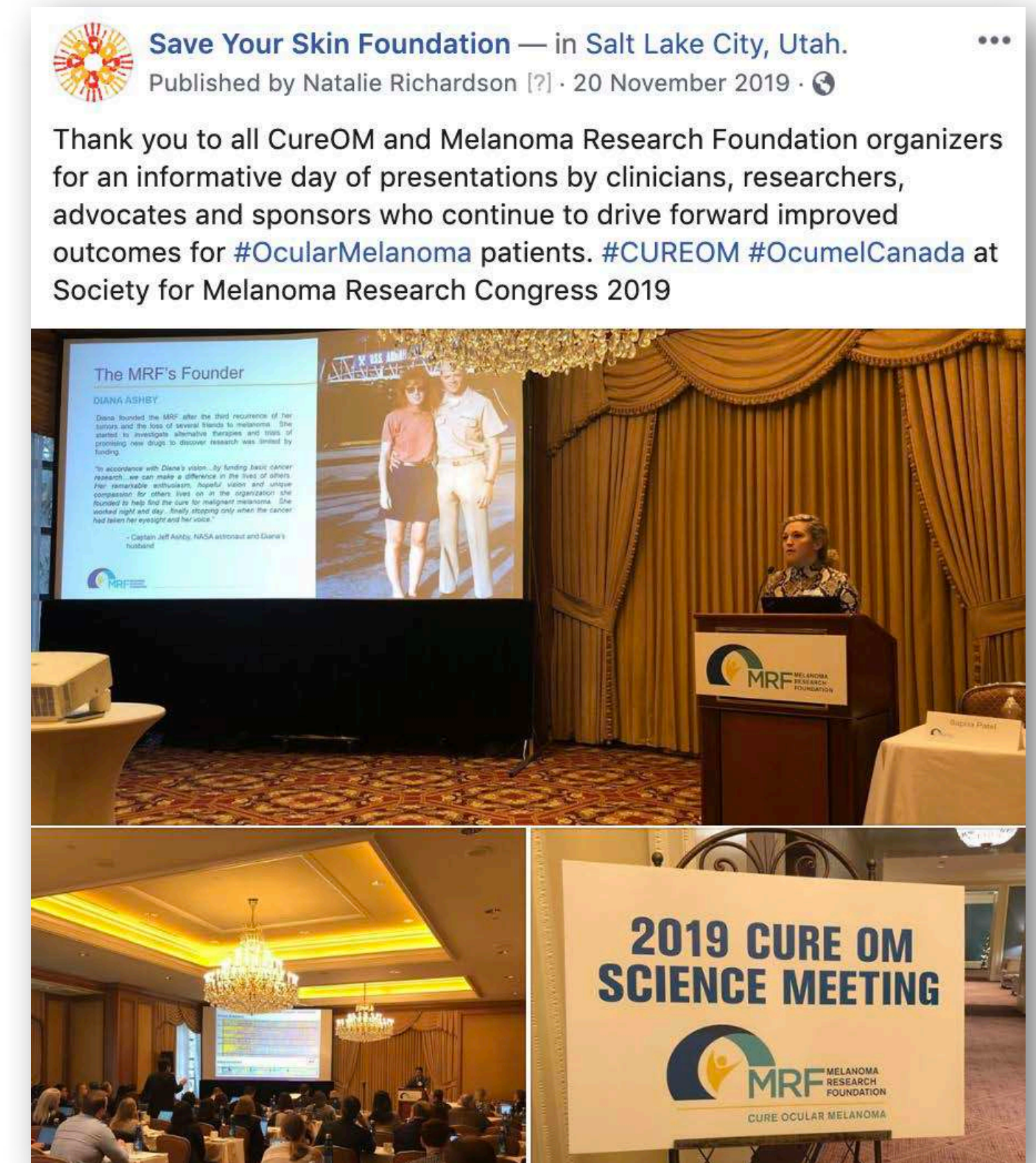
# 2019 Highlights



Promoted OC on Social Media



Announced the launch of First Global Patient Registry for Uveal Melanoma




Attended the Society for Melanoma Research Congress 2019

# 2019 Highlights



Fundraised for Ocular Melanoma Patients during Move for Melanoma 2019



 **Save Your Skin Foundation**  
Published by Marianne Gagnon · 3 December 2019 ·

On this [#GivingTuesday](#) CA, we'd like to invite you to support Ocumel Canada, an initiative that was created by Save Your Skin Foundation and ocular melanoma (OM) survivor and advocate Nigel Deacon in order to raise awareness for this rare disease and the patients who need support to handle it.

We are inspired by the feedback we receive from patients who need better support in their diagnoses of primary and/or metastatic ocular melanoma, to work toward better and more standardized care in all provinces in Canada.

Please help us in continuing this important work by making a donation to Ocumel Canada today.  
<https://www.canadahelps.org/.../campaign/ocumel-canada/>

*Why support a rare cancer like ocular melanoma?*

**CURE Ocular Melanoma**  
15 November 2019 ·

"There's such a need in this space that dollars may well go much farther and be more helpful with a rare disease ... your donations will make a big difference here." – Dr. David Eschelman

Fundraised for OM patients on Giving Tuesday



# 2019 Highlights

**Save Your Skin Foundation**  
Published by Marianne Gagnon · 4 November 2019 ·

Ocumel Canada has partnered with CureOM for this year's **#EyeGetDilated** awareness campaign! If you'd like to participate, please re-post information from the CureOM, [Melanoma Research Foundation](#), and Ocumel Canada social media channels during the month to spread the news about the importance of dilated eye exams, and share your own messages too! You can also request our free "Missing a Check?" postcards to take to your local doctors to include in their annual wellness reminders or download a PDF copy. Suggested places to hand out postcards/flyers (with permission) include your primary care/family physician, optometrist and dermatologist. Email us to find out more! [info@saveyourskin.ca](mailto:info@saveyourskin.ca)

## #EYEGETDILATED

- Doctor
- Dentist
- Dermatologist
- Dilated Eye Exam

**MISSING A CHECK?**

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



Ocumel Canada  
1-800-460-5832  
[ocumelcanada.ca](http://ocumelcanada.ca)  
[ocumelcanada@saveyourskin.ca](mailto:ocumelcanada@saveyourskin.ca)



This graphic was created with the permission of CureOM, an initiative of Melanoma Research Foundation [www.cureom.org](http://www.cureom.org)

**Save Your Skin Foundation**  
Published by Marianne Gagnon · 19 November 2019 ·

**CURE Ocular Melanoma**  
19 November 2019 ·

"Your eyes can hold secrets, sometimes dark ones." - Nigel Deacon, OM survivor, member of the CURE OM Patient Steering Committee and Co-founder of the [Save Your Skin Foundation's](#) Ocumel Canada initiative. Read more in the latest **#EyeGetDilated** guest blog post:

MELANOMA.ORG  
**#EyeGetDilated: Nigel D. | Melanoma Research Foundation**  
Guest blog post by Nigel Deacon, ocular melanoma survivor, member of the CURE OM Patient Steering Committee and Co-founder of Ocumel Canada: Why have your eyes examined? I will explain. Please read on...

**Save Your Skin Foundation**  
Published by Marianne Gagnon · 12 November 2019 ·

What is ocular melanoma (OM)? Watch this 60-second overview from Dr. Michael Brennan and find more information at [www.cureom.org](http://www.cureom.org). **#EyeGetDilated**

**Dr. Michael Brennan**  
Ophthalmologist, Retired

**CURE Ocular Melanoma**  
8 November 2019 ·

What is ocular melanoma (OM)? Watch this 60-second overview from Dr. Michael Brennan and find more information at [www.cureom.org](http://www.cureom.org). **#EyeGetDilated**

**Save Your Skin Foundation**  
Published by Marianne Gagnon · 15 November 2019 ·

**CURE Ocular Melanoma**  
14 November 2019 ·

Let's see those **#EyeGetDilated** selfies! This month we're raising awareness of the importance of dilated eye exams and our community is leading by example - if you have an exam scheduled, take and share a selfie to show the world that **#EyeGetDilated!**

Fun fact: although it is used primarily to test vision (so be sure to request a dilated eye exam, too!), the device you most often associate with an eye exam is called a "phoropter."

Took part in the **#EyeGetDilated** Campaign

# 2020 Highlights

## January

- Prepared 2020 Ocumel Canada Strategic Plan and created an Ocumel Canada contact card (English and French)

## February

- Launched 'Ocular Melanoma Connect' Facebook group

## April

- Met with Canadian Partnership Against Cancer re: Ocular Melanoma Care Pathways



## September

- Released Ocumel Canada Report on HCP Survey: "Understanding Ocular Melanoma Care Pathways in Canada"
- Raised almost \$20,000 for Ocular Melanoma patients through the Move for Melanoma 2020 event

## November

- Attended and presented at the Eyes on a Cure: Ocular Melanoma Patient and Caregiver Global Symposium
- Hosted OM Physician Roundtable

# 2020 Highlights

	<p><i>You are not alone</i></p>
<p><b>Ocular Melanoma (OM)</b></p>	<p><b>Ocumel Canada</b></p>
<p><b>OM is rare</b>, 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><b>Uveal Melanoma</b> - 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"> <li>• Choroidal melanoma</li> <li>• Iris melanoma</li> <li>• Ciliary melanoma</li> <li>• Conjunctival Melanoma</li> </ul> <p>For more info, watch our webinar: <a href="http://www.bit.ly/OcumelWeb">www.bit.ly/OcumelWeb</a></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 <a href="http://OcumelCanada.ca">OcumelCanada.ca</a> to find up-to-date educational and support resources from Canada, the United States, and around the world.</p>
<p>ocumel canada  AN INITIATIVE OF save your skin FOUNDATION</p>	<p><b>Ocumel Canada</b> 1-800-460-5832 ocumelcanada@saveyourskin.ca</p>

	<p><i>Vous n'êtes pas seul</i></p>
<p><b>Mélanome Oculaire (MO)</b></p>	<p><b>Ocumel Canada</b></p>
<p><b>Le mélanome oculaire</b> 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><b>Mélanome uvéal</b> - 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"> <li>• Mélanome choroïde</li> <li>• Mélanome de l'iris</li> <li>• Mélanome ciliaire</li> <li>• Mélanome conjonctival</li> </ul>	<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: <a href="http://SauveTaPeau.ca/OcumelCanada">SauveTaPeau.ca/OcumelCanada</a> 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 : <a href="https://www.facebook.com/groups/OcularMelanomaConnect">Fb.com/groups/OcularMelanomaConnect</a>.</p>
<p>ocumel canada  UNE INITIATIVE DE LA FONDATION sauve ta peau</p>	<p><b>Ocumel Canada</b> 1-800-460-5832 ocumelcanada@saveyourskin.ca</p>

Created an Ocumel Canada contact card in French and English

# 2020 Highlights



## **Understanding Ocular Melanoma Care Pathways in Canada**

A Report by Ocumel Canada, an initiative of Save Your Skin Foundation

Published the “Understanding Ocular Melanoma Care Pathways in Canada” report

# 2020 Highlights

**Save Your Skin Foundation**  
Published by Amy Rosvold · 11 February ·

Ocular melanoma is a challenge in so many ways. The small number of diagnoses in Canada does make it difficult for the mainstream Cancer Agencies to provide adequate services. In some provinces and territories, there are no services at all. Our goal is to help individuals affected by the disease in many ways, and, longer term, help Cancer Agencies to improve services to us. Learn more about our work at [www.ocumel.ca](http://www.ocumel.ca)



SAVEYOURSKIN.CA  
**Ocumel Canada**  
Ocumel Canada

**Save Your Skin Foundation**  
Published by Amy Rosvold · 22 January ·

UVA and UVB rays can cause or speed up several diseases of the eye or its supporting structures and because they occur over a long time, they may happen surreptitiously and are irreversible. That's why it's important to wear sunglasses with 99% to 100% UVA and UVB absorption. For more information on how to prevent ocular melanoma, visit: <https://saveyourskin.ca/ocumelcanada/>

**Save Your Skin Foundation**  
Published by Amy Rosvold · 19 October ·

Informed and empowered Ocular Melanoma patients live longer, better lives. [OcumelCanada.ca](http://OcumelCanada.ca) provides resources to help you get the information you need like questions to ask your doctor. Find this resource and more at [OcumelCanada.ca](http://OcumelCanada.ca)



SAUVETAPEAU.CA  
**Ocumel Canada**  
Ocumel Canada

**Save Your Skin Foundation**  
Published by Amy Rosvold · 30 November at 12:10 ·

Ocumel Canada is here to help Canadians diagnosed with Ocular Melanoma find the latest information information about the disease and a supportive community for patients and caregivers. [www.OcumelCanada.ca](http://www.OcumelCanada.ca)



SAVEYOURSKIN.CA  
**Ocumel Canada**  
Ocumel Canada

**Save Your Skin Foundation**  
28 February ·

Tomorrow is Rare Disease Day. Ocular melanoma is a rare disease. About 200 people are diagnosed in Canada per year. While it represents only 5% of melanomas, ocular melanoma is rapid and aggressive, accounting for 9% of melanoma deaths.

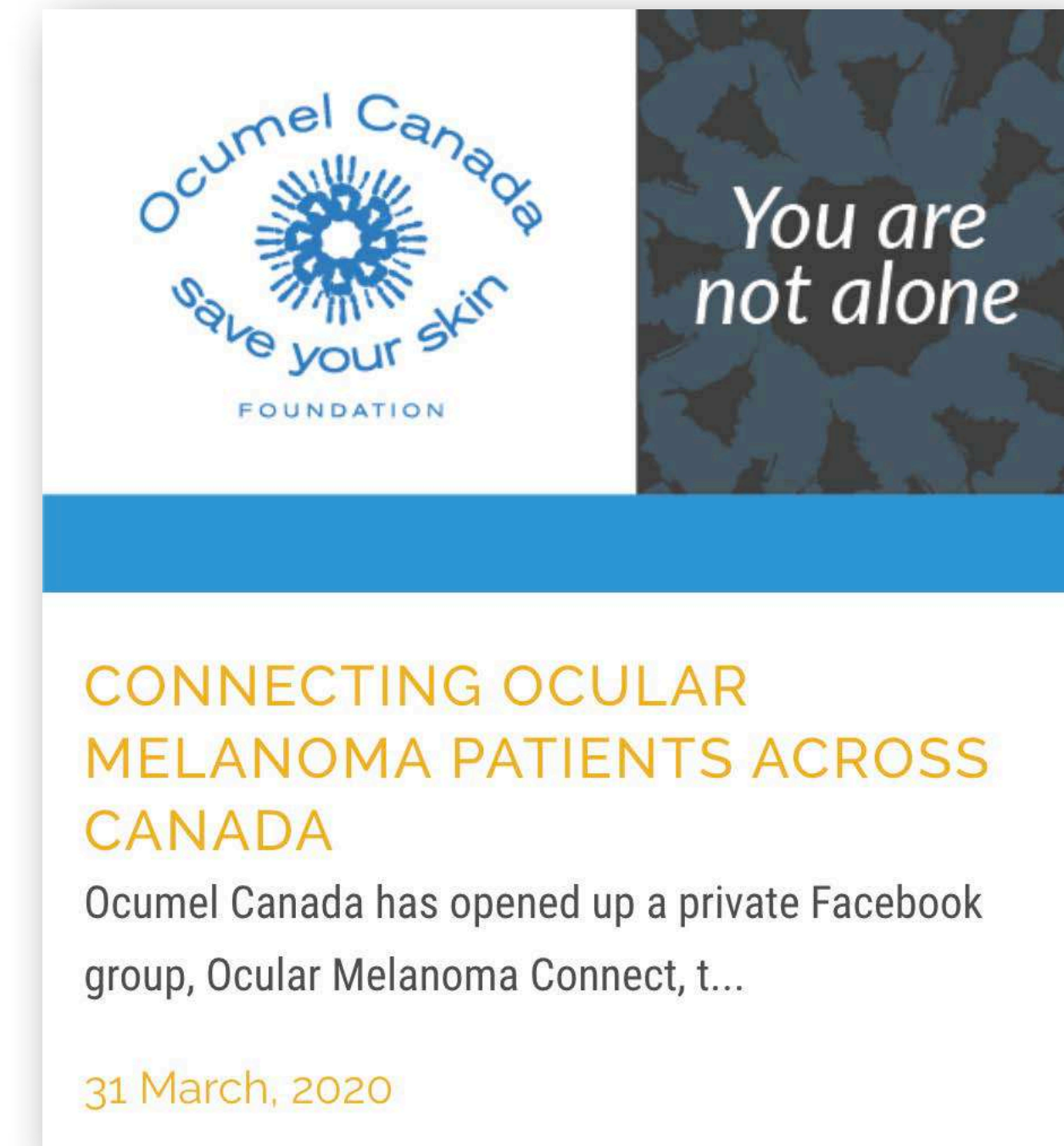


Promoted Ocumel Canada on Social Media

# 2020 Highlights



Created the Ocular Melanoma Connect Facebook group



Published a blog post to promote the Ocular Melanoma Connect Facebook group

# 2020 Highlights

EDMONTON SUN

## Rare cancer survivor paddling down North Saskatchewan River for melanoma research

Nathan Martin  
Sep 20, 2020 • Last Updated 1 month ago • 1 minute read



BC LOCAL NEWS  
Travel Cannabis 19+ Jobs Trending Now Business Contact Us



Nigel Deacon has run ultra-marathons before and says he's looking forward to running a marathon at the end of this month in support of the Move for Melanoma event. (Provided by Nigel Deacon)

## Victoria man to run marathon after overcoming rare cancer diagnosis

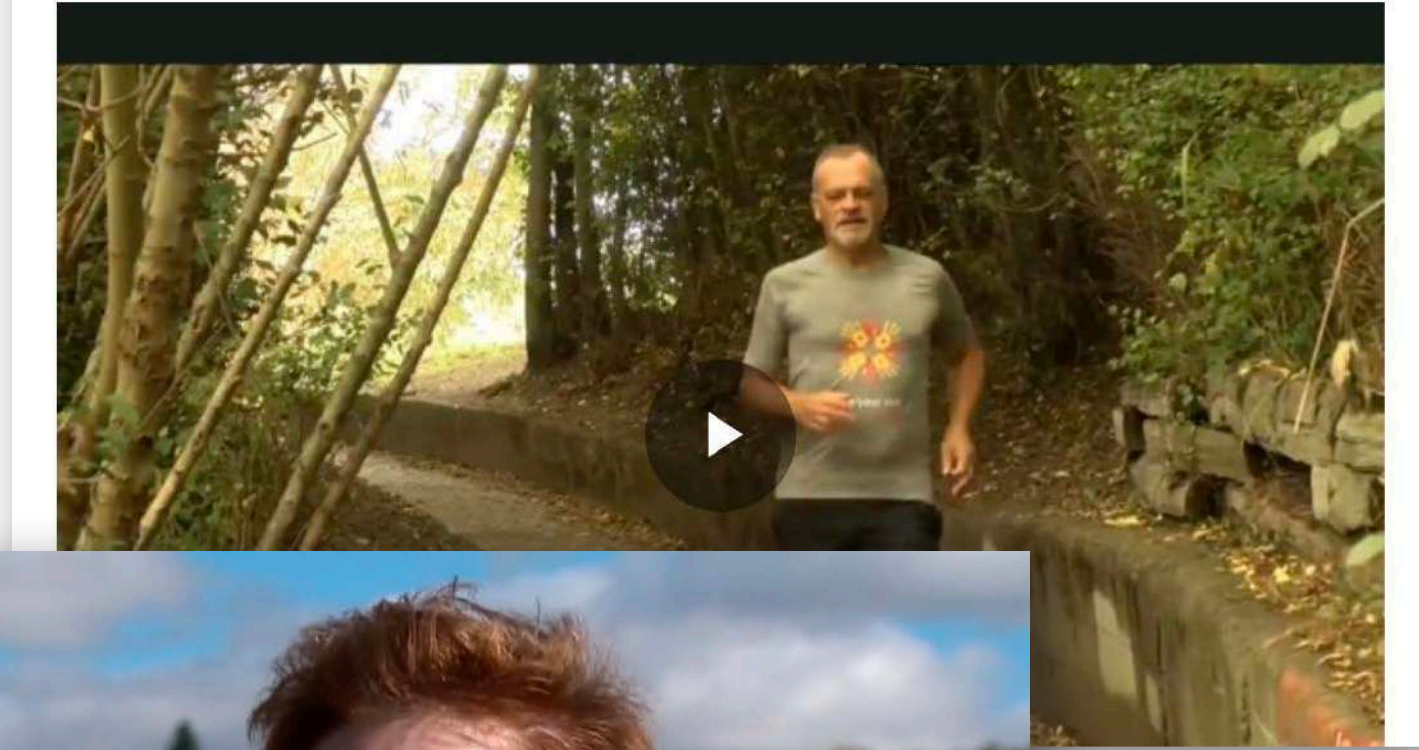
Nigel Deacon was diagnosed with ocular melanoma in 2010

Sep. 20, 2020 12:00 a.m. / NEWS

CHEK HOME NEWS COVID-19 SHOWS

## CHEK Upside: Victoria man who beat cancer set to run marathon

September 23, 2020 UPDATED



Fundraised for ocular melanoma patients during Move for Melanoma 2020

# 2020 Highlights

**MRF MELANOMA RESEARCH FOUNDATION CURE OCULAR MELANOMA**

ocumel canada AN INITIATIVE OF save your skin FOUNDATION

OcuMelUK

AOMA AUSTRALASIAN OCULAR MELANOMA ALLIANCE

OcumeIrl THE UNIVERSITY OF TEXAS MD Anderson Cancer Center Making Cancer History

**YOU'RE INVITED! | NOVEMBER 19-21, 2020**

**Eyes on a Cure: Ocular Melanoma Patient and Caregiver Global Symposium**

**Register Today!**  
www.melanoma.org/eyesonacure

VIRTUAL EVENT

THANK YOU TO OUR SPONSORS

MERCK NOVARTIS CASTLE BIOSCIENCES Alkermes IMMUNOCORE Bristol Myers Squibb

**Melanoma Research Foundation**  
12 November · 🌐

The CURE OM initiative's 9th Annual VIRTUAL Eyes on a Cure: Ocular Melanoma Patient and Caregiver Global Symposium is officially one week away on November 19-21, 2020. We have partnered with Ocumel Canada (an initiative of the [Save Your Skin Foundation](#)), [OcuMel UK](#), Ocumel Ireland and the Australasian Ocular Melanoma Alliance to provide insights on OM from around the world. Please go to <https://www.accelevents.com/e/CUREOMGlobal> to register! We have created a tutorial on how to use Accelevents and walk you through what the platform will look like when it opens for the event [https://www.youtube.com/watch?v=Kyo0G\\_yidiE&feature=youtu.be](https://www.youtube.com/watch?v=Kyo0G_yidiE&feature=youtu.be)

**Save Your Skin Foundation**  
Published by Amy Rosvold · 17 November · 🌐

Ocumel Canada is presenting and exhibiting at this year's CureOM Global Virtual Symposium which starts tomorrow.

The CureOM Symposium gives patients and caregivers the opportunity to learn the latest in research, treatments and social-emotional support from the leaders in the world of ocular melanoma.

**Eyes on a Cure: Ocular Melanoma Patient and Caregiver Global Symposium**

MRF MELANOMA RESEARCH FOUNDATION CURE OCULAR MELANOMA

ACCELEVENTS.COM  
**Event Page | MRF CURE OM Patient & Caregiver Symposium**

**Save Your Skin Foundation**  
Published by Natalie Richardson · 21 November at 12:21 · 🌐

Ocumel Canada wishes to Thank all Participants, Attendees and Organizers of the 2020 CureOM Global Symposium for an informative and interactive event this past few days. Special thanks to Canadian Physicians Dr. Julia Burnier (Montreal) and Dr. Marcus Butler (Toronto) for presenting their work at the Symposium and participating in the Live International Panel discussions – your collaboration and work in the diagnosis and treatment of ocular melanoma is immensely appreciated! [#GlobalOM2020](#)

All sessions have been recorded and are available for viewing at the CureOM event page for the next 30 days. Please visit to see Canadian and international group collaboration in the field: <https://www.accelevents.com/e/CUREOMGlobal>

MRF CURE OM Patient & Caregiver Symp... 📅 🔔 📷 Natalie

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Welcome from Ocumel Canada!

Kathy Barnard Nigel Deacon Natalie Richardson

www.OcumelCanada.ca ~ OcumelCanada@saveyourskin.ca

Day 3 Welcome from Canada!

CURE OM Patient & Caregiver Symp... 📅 🔔 📷 Natalie

University Health Centre Health Institute

Julia V Burnier Assistant Professor, of Oncology & Pathology, Principal Investigator, Research Program Liquid Biopsy Laboratory, Mental Pathology Unit

Arch: An International Overview Live Panel Discussion International Overview Live Panel Discussion

Attended and presented at Eyes on a Cure: Ocular Melanoma Patient and Caregiver Global Virtual Symposium, Nov 18-21 2020



# 2020 Highlights

**Eyes on a Cure: Ocular Melanoma Patient and Caregiver Global Symposium**

MRF CURE OM Patient & Caregiver ... Hello, Melanoma Research F...

Chat Polls People Q&A

Everyone Backstage

HOPE • LIVE

Bernadette Boyle  
Hi Nigel and Carla! Miss you both so much!

Nigel Deacon  
Oh Bernadette! Wonderful to see you! Next year?

Bernadette Boyle  
I hope we can all be back together in 2021

Nigel Deacon

type your message

HOPE

Session Details Speakers Up Next

#EYGETDILATED

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# 2020 Highlights

## #EYEGETDILATED





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**ALISON, VICTORIA, BC**

"It had been two years since my last regular eye exam with my optometrist. I started to notice what I called milky spots, (white flashes), floating across my vision when I closed my eyes to go to sleep. I didn't think much of them until they presented more frequently and I had experienced sharp pain in my right eye a couple of times. I decided it would be wise to make an appointment with my optometrist. During my exam, I told my optometrist about the white flashes. He suggested that I have a digital image taken of my eyes.

We took the images and then when he viewed them he was concerned about what he saw. He showed me the image of my right eye and I could see a mass that very clearly shouldn't have been there. That was the beginning of my diagnosis of Ocular Melanoma.

I was treated four months later with brachytherapy of the right eye. The plaque filled with radiated seeds was placed at the back of my right eye and remained there for one week. The surgeries for placement and removal of the plaque were successful and so began the slow process of the tumour shrinking and dying. I have lost clear vision in my right eye but am grateful that my eye could be preserved.

I know now that the white flashes and pain I experienced was my retina detaching due to the fluid leaking from the tumour. I encourage everyone I talk to about my diagnosis to get a yearly eye exam that includes dilation and to never ignore any changes in vision."

**MISSING A CHECK?**  
Ask your Optometrist about the importance of early detection of Ocular Melanoma

BC DOCTORS OF OPTOMETRY

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- Dentist
- Dermatologist
- Dilated Eye Exam

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For more information contact [ocumelcanada@saveyourskin.ca](mailto:ocumelcanada@saveyourskin.ca) | 1-800-460-5832

## #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."

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**Save Your Skin Foundation**  
Published by Amy Rosvold · 2 November ·

November is the month to bring awareness to the importance of Dilated Eye Exams for the early detection of ocular melanoma. [#EyeGetDilated](https://www.instagram.com/ocumelcanada/)

**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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Participated in the #EyeGetDilated Campaign

# 2020 Highlights

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**OM Physician Roundtable Agenda:  
Understanding Ocular Melanoma Care Pathways in Canada**

**Introductions**

a) Kathy Barnard, Natalie Richardson, and Nigel Deacon  
b) Physician Panel Attendees

- Dr. Thao Nguyen, BC Cancer, Abbotsford
- Dr. Katherine Paton, UBC, Vancouver
- Dr. Ezekiel Weis, Royal Alexandra Hospital, Edmonton
- Dr. Smylie, Cross Cancer Institute, Edmonton
- Dr. Marcus Butler, Princess Margaret Cancer Centre, Toronto
- Dr. Rahima Jamal, CHUM, Montreal

**Discussion Points on Primary and Metastatic Ocular Melanoma:**

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

**Closing Remarks & Next Steps**

*Facilitator: Kathy Barnard, Ocumel Canada  
November 12, 2020  
www.OcumelCanada.ca*


**Our 2020 strategic plan**

**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

**Our core values**

-  Compassion for Patients and Caregivers
-  Passion for Promoting Access to Patient Care
-  Bold in Science
-  Devotion to Improving Ocular Melanoma Patient Outcomes

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Hosted OM Physician Roundtable

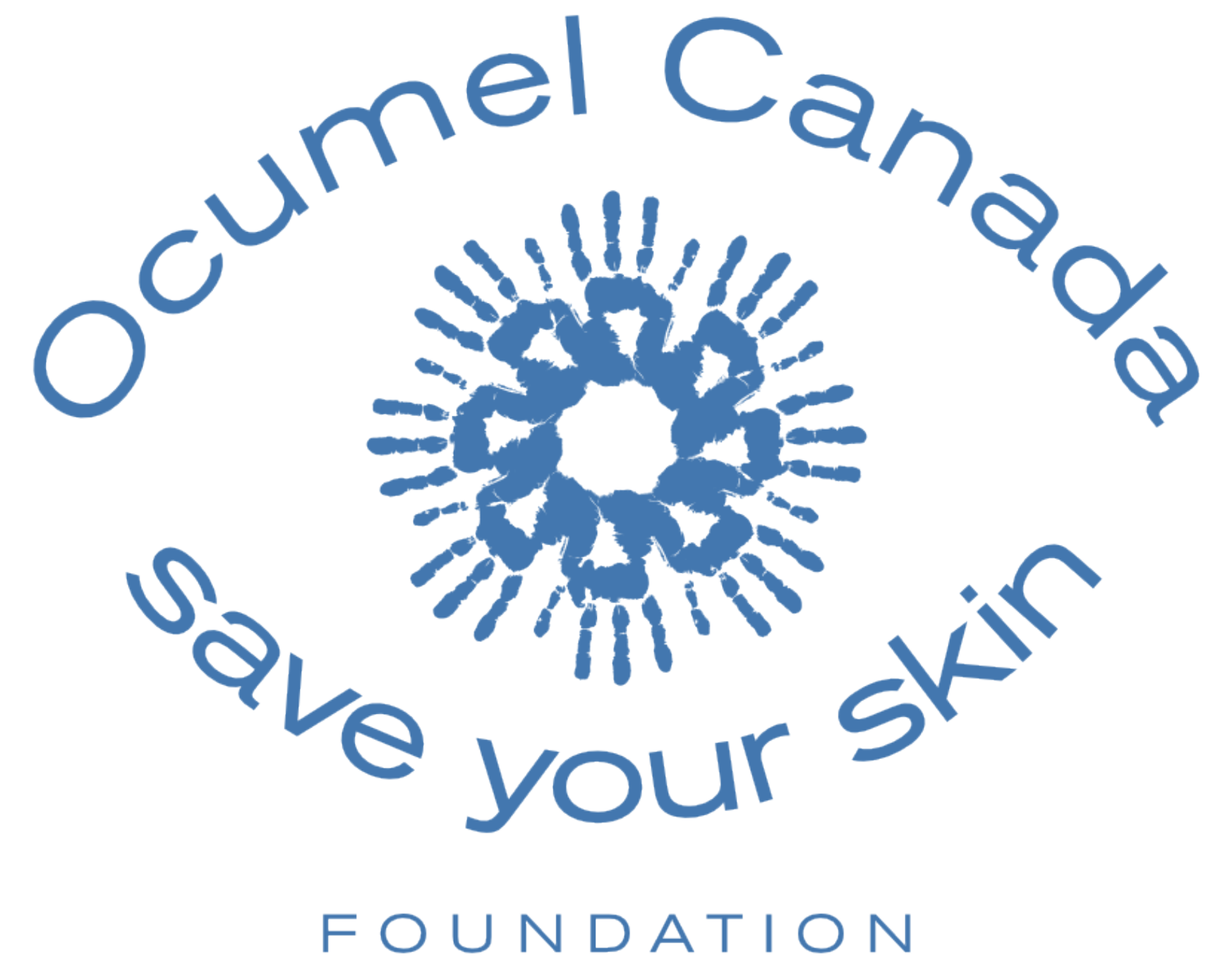
# Looking Ahead

In the coming year, we will be focussing on reaching more Canadian ocular melanoma patients and offering our support and information to them.

Our Facebook group, Ocular Melanoma Connect, continues to grow and provide a meeting place for Canadian OM patients and caregivers to connect, share resources, and provide emotional support.

We are also excited about the formation of a national taskforce of ocular melanoma doctors.

We are at the beginning of a long journey. But there is hope.



# Thank You to our Sponsors

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