

ocumel canada



AN INITIATIVE OF  
**save your skin**  
FOUNDATION

**Understanding Ocular Melanoma Care Pathways in Canada**

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

September 2020

## INTRODUCTION

Ocular, or uveal, melanoma is a rare disease. There are many and varying estimates as to how many diagnoses are made every year. In the United States, estimates tend to vary between 1,500 and 2,500 new cases per annum<sup>1</sup>. In Canada, an educated guess would suggest that we see perhaps 200 new cases per annum. Half of those would occur in Quebec and Ontario, where more than half of the population lives. ([additional information](#))

Most tumours arise in the choroid (over 90%) at the back of the eye but can also appear in the iris, the ciliary body and the conjunctiva.

Known risk factors remain out of the control of patients for now. The greatest risk is having fair skin and blue/green eyes. Also, most diagnoses occur in people around the age of 60. There is a very small proportion of ocular melanoma patients with a germline BAP1 mutation, putting them at higher risk of several cancers. There appears to be a slightly higher risk for males than females but this difference may disappear as more evidence accumulates.

Nevertheless, ocular melanoma (OM) can appear in children and the aged, and in people with any kind of skin colour.

We know from many studies that almost 50% of primary diagnoses will metastasize, many at around the two-year mark and almost all within five years. There are however cases where metastasis occurs within months or even after twenty years from primary diagnosis.

Recent learnings from genetic mapping of the disease have provided much deeper insight into the genetic mutations found in ocular melanoma patients. It is now clear that it is a cancer with a very low number of mutations. While this might make it appear easier to find therapies, it actually provides fewer targets for current therapies. The extraordinary progress made recently in treating cutaneous melanoma has not been replicated yet in ocular melanoma.

The greatest advance in recent years has been the availability of testing of the primary tumour, through a biopsy, to establish the risk of metastatic disease. There are several tests available and several of our centres routinely perform biopsies, wherever possible, at the time of primary treatment. This increased knowledge is helpful to both doctors and patients. Half of the primary patients end up knowing that they are very unlikely to have any further issues with their cancer. The other half is able to make a better plan for surveillance and hopefully be able to intervene earlier in the course of metastatic disease. Early intervention offers more treatment opportunities.

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<sup>1</sup> Aronow, M.E. et al (2018). Uveal Melanoma: 5-Year Update on Incidence, Treatment, and Survival. *Ocular Oncology and Pathology* 2018;4:145–151. Retrieved from <https://www.karger.com/Article/Fulltext/480640>

## Primary diagnosis

In many cases, patients have few or no symptoms at the time of primary diagnosis. Visual disturbances can be dramatic or almost imperceptible. The importance of regular comprehensive eye exams with dilation for everyone must be stressed as it would lead to earlier diagnosis of ocular melanoma. Smaller tumours are less dangerous than larger tumours. Treatment of smaller tumours may lead to reduced vision loss.

The disease is generally diagnosed by ocular oncologists in specialist centres. Most tumours are treated with brachytherapy but enucleation is sometimes necessary. Proton beam therapy is vision sparing in some cases but not easily accessible in Canada. A new light activated therapy is currently in clinical trials in the US and shows promise.

Patients who have had treatment for primary disease are followed by the specialist centres as vision deficits and eye health issues are common. Treated tumours in a small percentage of cases can start to regrow and need further treatment. Patients can now, in almost all cases, have a biopsy to determine the risk of metastasis. This is very helpful in designing an appropriate follow up protocol.

## Metastatic diagnosis

The development of metastatic disease, especially in high risk patients, is usually detected by regularly scheduled abdominal MRIs and CTs of the lungs. Metastasis to brain, lymph nodes or bones and soft tissue, is uncommon but possible. Liver involvement is almost universal.

There are currently no approved treatments anywhere in the world for metastatic ocular melanoma (MOM).

## Additional resources to illustrate the current landscape of research:

[Nature Reviews Disease Primers – Uveal Melanoma](#), April 9, 2020

[Sequencing of 117 Routine Clinical Samples Provides Further Insights into the Molecular Landscape of Uveal Melanoma](#) - *Cancers* **2020**, *12*, 1039.

[Shift in Treatment Modalities Associated with Improved Outcomes in Uveal Melanoma Patients with Liver Metastasis](#) - Thomas Jefferson University, February 3, 2020

## **OCUMEL CANADA SURVEY OF OM HEALTH CARE PROVIDERS – CROSS-COUNTRY CHECK**

From August 28, 2019 to August 31, 2020, Ocumel Canada, an initiative of the Canadian melanoma patient support organization Save Your Skin Foundation, ran the survey “HCP Survey: Understanding Ocular Melanoma Care Pathways in Canada,” which assessed the services provided by centres working in the ocular melanoma treatment landscape. The survey was run through the SurveyMonkey platform, and consisted of a mixture of multiple choice and short-answer questions. There were twenty-eight (28) questions in total. Each question allowed participants the opportunity to comment, should they feel the need to elaborate on their experiences. The platform also offered the option for participants to skip questions.

The following report is based on the results of the “HCP Survey: Understanding Ocular Melanoma Care Pathways in Canada” survey. For access to the original survey data, contact [Save Your Skin Foundation](#).

## **Statistics**

The recording and tracking of ocular melanoma diagnoses across Canada is unclear and inconsistent. Some centres maintain centre-specific statistics and some have provincial systems in place. The need for patients to travel out of province or territory for treatment muddles the situation considerably as it is not clear in which province or territory the case is recorded, if at all.

The Canadian Cancer Society, in its publications, conflates all eye cancers, making it impossible to distinguish between uveal melanoma, conjunctival melanoma, lymphoma, retinoblastoma and other even rarer eye cancers.

The first global patient driven registry, developed by CureOM in the United States, and supported by Ocumel Canada, will launch in late 2020 and will provide an opportunity for patients to register themselves and provide a detailed record of their disease. The registry will be cross-referenced to a global medical Ocular Melanoma Registry launched in 2019. This patient driven registry has the potential to develop much more accurate information over time about ocular melanoma if it is well subscribed.

## **Clinical trials**

Since there is not yet any approved systemic treatment for metastatic ocular melanoma, it is recommended that patients participate in clinical trials as the standard of care. This is a very frustrating situation for Canadian patients as there are very few clinical trials available anywhere across the country. While there are currently 19 active clinical trials for MOM in Europe and the United States, only one of them is available to Canadian patients. See Table 1 in the landscape OM article included (above) for a list of the trials available elsewhere.

Trials in the adjuvant setting are very rare. Patients identified as at a high risk for metastases find themselves in a helpless situation.

## **Treatment guidelines**

Alberta and Ontario have provincial guidelines in place. Quebec guidelines are under review. British Columbia appears to have no guidelines.

## **The Canadian context**

There are four specialist centres in Canada for ocular melanoma patients.

### Alberta

Alberta has clinics in both Calgary and Edmonton where primary disease is diagnosed. Treatment of primary and metastatic disease is available at Royal Alexandra and the Cross Cancer Institute in Edmonton.

Contact information: [Alberta Health Services](#)

### British Columbia

Primary disease is treated at the Eye Care Centre in Vancouver. Biopsies appear to be available but there is no financial support for patients who request them. There appears to be no routinely scheduled monitoring for the development of metastatic disease. Metastatic patients, when diagnosed, appear to be randomly assigned to oncologists.

Contact information: [BC Cancer](#)

### Ontario

Ontario concentrates treatment of primary and metastatic disease at Princess Margaret Cancer Centre in Toronto and patients travel from many parts of Canada to receive care there.

Contact information: [Princess Margaret Cancer Centre](#)

### Quebec

Treatment for primary and metastatic disease is available in Montreal. There is a lively research arm in Quebec, with at least two labs doing research directly linked to ocular melanoma.

Contact information: [CHUM](#)

### Additional resources

Patients in Eastern Canada may have the option of receiving post-brachytherapy care from ocular oncologists closer to home. For more information please contact:

#### [Memorial University](#)

St. John's, NL

#### [Dalhousie University](#)

Halifax NS

**Table 1 - Summary of available treatments as per Ocumel Canada 2020 HCP Survey:  
“Understanding Ocular Melanoma Care Pathways in Canada”**

Treatment	Alberta	BC	Ontario	Quebec
Primary:				
Brachytherapy	√	√	√	√
Proton beam	√	√	√	√
Enucleation	√	√	√	√
Wait time	4 weeks	2 to 4 weeks	2 weeks	4-6 weeks
Genetic testing	yes	yes	yes	yes
Metastatic:				
Liver directed				
Ablation	√	√	√	
Surgery	√	√	√	√
Radiotherapy	√	√	√	√
SBRT	√	√	√	√
Chemoembolization	√	√	√	√
Immunoembolization	√	√		
Radioembolization				
Systemic:				
Immunotherapy	√	√	√	√
Tebentafusp	√		√	
Targeted:				
Sunitinib	√			

Table 1 – Note: None of the treatments for metastatic disease listed for BC have been confirmed by a treating oncologist.

## LEARNINGS

### Patient challenges

Ocular melanoma is a challenging diagnosis to live with. A 2018 report by Ocumel Canada, revealed the need for more patient support, from medical teams and from the advocacy and patient community. Click here to read the full report: "[Save Your Skin Foundation Patient Survey: Understanding Ocular Melanoma in Canada](#)"

Patients appear to be treated quite differently in some treatment centres than in others. A biopsy is routine in some centres and not in others. There are significant variations in tracking after diagnosis. Some provinces have clear and recent guidelines available. Others do not. Information to guide new and returning patients is readily available online for some centres, not in others.

Travel costs, for patients who live far from the treatment centres, is a major challenge. Some provinces have a plan in place to fund or subsidize necessary travel but others do not. A consistent approach across the country would be a very welcome development. At the time of primary treatment, accommodation costs can accumulate also and this is a financial burden for some. Many patients have to travel long distances and out of province and territory for treatment.

## LOOKING AHEAD

### Coordinating our approach

There are some heroic efforts being made across Canada, in research, treatment and follow up in ocular melanoma. However, it would be beneficial to patients if bridges among centres could emerge over time. In other countries, such as the UK, a coordinated national approach has been a boon to patients for many years. Canada's universal healthcare system, though province and territory based, should make better communication and coordination possible and it is certainly desirable from the patient perspective.

Empowering patients to advocate for themselves: better follow up, appropriate treatments, routine biopsies where possible, access to clinical trials, social/emotional support and financial support would help patients deal with their challenging diagnosis. There is a clear role for patient advocacy organizations such as Ocumel Canada in this area.

Canadians give enormous financial support for cancer research each year. Creating interest in funding research into ocular melanoma in particular at this critical juncture would be timely and important.

There are not many cancers which have not responded to improvements in treatment over the past few decades. Metastatic ocular melanoma remains sadly a major challenge. With focus,

support, research, funding and coordination of communication and best practices in patient care, we can do better.

### **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 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. Save Your Skin Foundation (SYSF) is a national patient-led not-for-profit group dedicated to the fight against non-melanoma skin cancers, melanoma and ocular melanoma through nationwide education, advocacy, and awareness initiatives. Save Your Skin Foundation is committed to playing an active role in reducing the incidence of skin cancer in Canada, and to providing compassionate support for all Canadians living with skin cancers.

To learn more please view these links:

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

[Ocumel Canada – Patient Support Forum](#)