

# Patient Advocacy Campaign

Yervoy defunding and the lack of transparency by the  
Canadian Drug Implementation Advisory Committee

save your skin  
FOUNDATION



LA FONDATION  
sauve ta peau

# Overview

The major concerns of the ongoing Yervoy funding concern is two-fold. This issue began in November 2016 when all public drug plans across Canada suddenly, and without consultation with experts, defunded Yervoy, leaving many patients unable to access this potentially life-saving treatment. Kathy Barnard, founder of the Save Your Skin Foundation, owes her own survival of metastatic melanoma to Yervoy, which she received in a clinical trial, after failing on all previous treatments. This led to awareness about an even larger issue concerning the newly formed CDIAC (Canadian Drug Implementation Advisory Committee).

In early 2016, the Canadian Association of Provincial Cancer Agencies (CAPCA) formed the CDIAC to provide recommendations on integrating new cancer drugs into existing treatment pathways and to achieve greater consistency in drug funding decisions across Canada. Although active, CAPCA did not introduce the CDIAC initiative to the cancer community.

We have never seen the parameters and guidelines for its recommendations. All of its recommendations on cancer drugs been kept secret We do not know if any recommendation changed any drug access outcome. The Foundation, along with the Canadian Melanoma Task Force of Oncologists believes the CDIAC has made recommendations on drugs that are not aligned with accepted clinical practice, resulting in reimbursement decisions that differ from other pan-Canadian recommendations. The continued lack of transparency causes confusion, and a degree of suspicion.

# Overview

Melanoma treatment is a prime example of how the current review process has failed patients. In 2012, Yervoy, the first-generation checkpoint inhibitor, was approved. Today, 25% of treatment-naïve patients who received Yervoy experience long-term survival, compared with a historical survival of 5 to 10%. Now, with newer checkpoint inhibitors, Keytruda and Opdivo, survival with these drugs is superior to Yervoy. They are generally used as initial treatments in metastatic melanoma.

However, Yervoy is effective in some patients who have failed Keytruda and Opdivo. So why, one year ago, did all public drug plans suddenly, and without consultation with experts, defund Yervoy? Canada is the only western country to defund this therapy. Today, with new scientific evidence that Yervoy provides clinical benefit as a second-line therapy, there has been no change in public funding and no promise to re-evaluate the decision.

However, for patients in the public system, life and death decisions are being made behind closed doors with no accountability to the people who are impacted directly by this judgment. Our advocacy campaigns aims to urge the current decision makers on health care access to open up the review process and consider, fully, the far-reaching impact of their decisions.

# Tactics

## **2016**

Foundation letter to Ministers of Health, pCODR, pCPA and CADTH

Canadian Melanoma Task Force Physicians letter to Federal Minister of Health

National Press Release

Media campaign

Patient Survey

Patient Advocacy letter template, MoH list, fact sheet and speaking points

## **2017**

Government meetings

National Press Release

Twitter campaign

Opinion Editorials

# Foundation letter - Nov 2016



Imran S. Ali  
Senior Manager  
pan-Canadian Pharmaceutical Alliance (pCPA)

November 21, 2016

**Subject: *ipilimumab (Yervoy) funding recommendations for the treatment of advanced, unresectable or metastatic melanoma***

Dear Mr. Ali,

The Save Your Skin Foundation is a national not-for profit patient organization dedicated to skin cancer and the patients affected by it. Part of our mandate is ensuring that patients have access to timely and appropriate treatments. We have been following the provincial funding criteria for the innovative medicines for melanoma closely and we, as well as our medical experts, are concerned with the guidelines that have been established for ipilimumab.

[Read more](#)

# Sent to:

Hon. Kelvin Goertzen, Minister of Health, Seniors and Active Living (Manitoba)  
Hon. Jim Reiter, Minister of Health (Saskatchewan)  
Hon. Sarah Hoffman, Minister of Health (Alberta)  
Hon. Terry Lake, Minister of Health (British Columbia)  
Hon. Mike Nixon, Minister of Health and Social Services (Yukon)  
Hon. George Hickes, Minister of Health (Nunavut)  
Hon. Glen Abernethy, Minister of Health and Social Services (Northwest Territories)  
Dr. Malcolm Moore, President and Chief Executive Officer, BC Cancer Agency  
Dr. Michael Sherar, President and Chief Executive Officer, Cancer Care Ontario  
Dr. Verna Yiu, President and Chief Executive Officer, Alberta Health Services  
Scott Livingstone, President and Chief Executive Officer, Saskatchewan Cancer Agency  
Dr. Sri Navaratnam, President and Chief Executive Officer, Cancer Care Manitoba  
Dr. Michael Mayne, Chief Executive Officer, Health PEI  
David S. Diamond, President and Chief Executive Officer, Eastern Health  
Chris Collier, Interim Chief Operating Officer, Cancer Care Nova Scotia  
Dr. Eshwar Kumar, Co-Chief Executive Officer, New Brunswick Cancer Network  
Dr. Réjean Savoie, Co-Chief Executive Officer, New Brunswick Cancer Network  
Dr. Brian O'Rourke, President and Chief Executive Officer, Canadian Agency for Drugs and Technologies in Health (CADTH)  
Alex Chambers, Director, pan-Canadian Oncology Drug Review (pCODR)  
Suzanne McGurn, Assistant Deputy Minister and Executive Officer, Ontario Public Drug Programs  
Judith McPhee, Executive Director, Nova Scotia Pharmaceutical Services  
Imran S. Ali, Senior Manager, pan-Canadian Pharmaceutical Alliance (pCPA)



# Physicians letter - Nov 2016

Hon. Jane Philpott  
Federal Minister of Health  
Confederation Building, Suite 162  
House of Commons  
Ottawa, Ontario  
K1A 0A6

November 28, 2016,

**Subject: ipilimumab (Yervoy) funding recommendations for the treatment of advanced, unresectable or metastatic melanoma**

Dear Minister Philpott,

We are writing on behalf of the Canadian Melanoma Physicians Task Force (CMTF). This is a national interdisciplinary group of expert physicians involved in the care of melanoma patients in Canada.

Recently Save Your Skin Foundation issued a press release regarding the issues

[Read more](#)

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Hon. Jim Reiter, Minister of Health (Saskatchewan)  
Hon. Sarah Hoffman, Minister of Health (Alberta)  
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Suzanne McGurn, Assistant Deputy Minister and Executive Officer, Ontario Public Drug Programs  
Judith McPhee, Executive Director, Nova Scotia Pharmaceutical Services  
Imran S. Ali, Senior Manager, pan-Canadian Pharmaceutical Alliance (pCPA)



# Press Release - Nov 2016



FOR IMMEDIATE RELEASE  
Media Contact:  
Karran Finlay  
T: 778-988-8194  
karran@saveyourskin.ca

## IMPORTANT NEW CANCER TREATMENTS APPROVED BY HEALTH CANADA MARRED BY MAJOR PROVINCIAL REALITY DISCONNECT FOR PATIENTS

*Patient access to innovative new cancer treatments seriously limited by provincial funding recommendations across Canada*

**TORONTO – NOVEMBER 22, 2016** - Health Canada recently conditionally approved an advanced new treatment option for Canadians battling metastatic melanoma. The treatment consists of a combination of two immuno-oncology agents: Opdivo + Yervoy, the first combination in the immunotherapy space. While many applauded the approval, numerous patients and doctors are holding their breath to see what provincial recommendations will come if approved for reimbursement by the pan-Canadian Oncology Drug Review (pCODR). Across Canada, cancer patients are being restricted to access to innovative new treatments due to funding recommendations made by health technology assessment agencies and provinces. Over the past year, patient access to some cancer treatments approved by Health Canada have been seriously limited as the result of these recommendations.

In June 2016 the first PD-1 immuno-oncology treatment for melanoma, Keytruda, was listed to the provincial formulary with a recommendation to fund either Keytruda or Yervoy, but not both – so that anyone having received either of these treatments through standard treatment or in a clinical trial as of June 2, 2016 would not have access to any other immuno-oncology treatment, regardless of having two distinct mechanisms of action. Meaning any patient who does not respond to one immunotherapy has no opportunity to access a second line therapy option (in the BRAF wildtype population).

[Read more](#)

# Earned Media



Victoria resident Nigel Deacon was diagnosed with metastatic melanoma in 2012.

Foundation calling for access to  
better cancer treatments

Victoria News, November 2016

# Earned Media

**THE BLOG**

## Lengthy Cancer Drug Approval Process Makes Me Fear For My Future

🕒 11/28/2016 04:31 EST | Updated 11/28/2016 04:32 EST

[f](#) [t](#) [p](#) [G+](#) [t](#)

 **Natalie Richardson**   
Mother, writer, metastatic melanoma survivor and advocate



BERNIE\_PHOTO VIA GETTY IMAGES  
Health care Cost statistics with stethoscope and Calculator



Huffington Post, November 2016



# Earned Media



New way to fight cancer: using your own immune system

Global National, November 2016



# Earned Media



660 News, November 2016

# Patient Letter Template

Date

Firstname Lastname, MLA or MPP

Street address

City/town

Postal Code

Dear Mr/Ms Lastname,

As a member of your constituency and as someone personally touched by cancer, I am writing to you regarding the critical need for equal timely access to new treatments for melanoma patients in (Province). It is important to recognize both the amazing strides that innovative cancer treatments have been making in increasing survivorship rates over the last decade; yet there is still much improvement to be made regarding the treatment approval process, and patients receiving equal and timely access to appropriate treatments.

When I was diagnosed with melanoma in (year), there were fewer treatment options than there are today, and the medical system was more difficult to navigate. (Can include more details of personal experience here). While improvements have been made, there remains the necessity for us as a community for us to work harder on behalf of all Canadian melanoma patients.

Though the melanoma treatment landscape is rapidly evolving, melanoma incidence rates are rapidly rising, creating the need for continuous innovation. The Canadian Cancer Society (CCS) estimated that in 2016, over 202, 400 Canadians would be diagnosed with skin cancer, with 6, 800 of these being melanoma, the most deadly form; the CCS estimated mortality rates for melanoma to be 1, 120 Canadian deaths. These rates have risen since 2014, which saw 6, 500 melanoma diagnosis' and 1, 050 deaths. Therefore, the fight for innovative treatments and an effective medical system for patients continues to be critical. I am writing to you as my elected representative to ask that you consider the need to immediately provide new, innovative treatments as a first line choice for patients and their health care providers throughout Canada through public funding. Though medical advances have made great progress toward survivorship, there is still more work to be done. I thank you for your consideration.

Sincerely,

Your name

Street address

City/town

Postal code

Phone number if applicable

Save Your Skin Foundation has assembled materials to assist you to do the following:

1. Write to your Members of Parliament to share your thoughts on this issue or to request a meeting – **contact information for local government members can be found [here](#).**
2. Write to your MLA/MPP asking that he/she write to the Minister of Health ([click here to download sample letter](#))
3. Prepare for and have a meeting with your MLA ([talking points](#) and [fact sheet](#))
4. Report back the results of your MLA meeting – contact us by email or phone any time
5. Write a letter for your MLA to send to the Minister of Health
6. Write to your provincial Ministers of Health (Click [here](#) to find out who your provincial Minister of Health is).
7. Write to the Minister of Health – contact information can be found [here](#) for Federal Minister of Health: Hon. Dr. Jane Philpott.

## Provincial/territorial ministries of health

- [Health insurance cards](#)
- [Ministries of health web sites](#)

[Read more](#)



# Fact Sheet | Speaking Points



## MELANOMA FACT SHEET

### About Melanoma in Canada

Melanoma is a deadly form of skin cancer. In 2016, 6,800 Canadians were diagnosed with melanoma and 1,120<sup>1</sup> succumbed to the disease. Skin cancers are the most commonly diagnosed form of cancer in Canada, despite being largely preventable. The preventability and high mortality rate of melanoma mean that fighting this disease requires a twofold approach: continual education and awareness initiatives, and increased equal and timely access to innovative treatments for patients who are diagnosed.

### Prevention plays an essential role

Melanoma is clearly visible on the skin, and 90 per cent of melanomas are caused by exposure to UV light, including tanning beds. Skin cancer is caused by overexposure of the skin to UV radiation. The most common sources of UV radiation on the skin are the sun and artificial tanning beds.

### Early detection increases survival

Moles, spots and certain growths on the skin are often harmless, but not always. That is why it is important to examine the skin all over your body once a month, and have a physician check your skin once a year.

Look for the following "ABCDE" warning signs:

- Asymmetry: Do the two halves not match if you imagine drawing a line through the mole?
- Borders: Are the edges uneven, scalloped or notched?
- Colours: Is there a variety of shades (brown, red, white, blue or black)?
- Diameter greater than 6mm: Is the mole the size of a pencil eraser or larger?
- Evolution: Has there been a change in size, shape, colour, or height? Has a new symptom developed (such as bleeding, itching or crusting)?

If you detect any of these warning signs, see a physician promptly. It is particularly important for you to select a physician who specializes in skin cancer and is trained to recognize a melanoma at its earliest stage.

### Treatment Innovations for Melanoma

Over the last decade, several forms of innovative treatments for melanoma including immuno-oncological therapies, biotherapies, and targeted therapies have been developed, and clinical trials have often demonstrated that these therapies can provide better patient outcomes than standard cancer therapies in terms of both survival rates and quality of life. However, these treatments are often kept from patients who need them in due to budgetary restrictions and lengthy approval times. It is therefore imperative that all stakeholders in the medical system work to address these barriers to patient access, in order to get lifesaving drugs in to the hands of patients who urgently need them.

If you have additional questions, please refer to our website [www.saveyourskin.ca](http://www.saveyourskin.ca) or email [kathy@saveyourskin.ca](mailto:kathy@saveyourskin.ca).

<sup>1</sup> All statistics supplied by the Canadian Cancer Society

## Script Outline For MLA Meetings

1. Introduce yourself and the person(s) with you. REMEMBER – it is important that you always take at least one other person with you. Make sure to note that you live in the riding. If asked if you represent anyone other than yourself, you can mention that you're part of a group of patients and caregivers concerned about access to medications, particularly medications for metastatic melanoma.
2. Explain that you are there to discuss a decision by Health Canada to approve the medication \_\_\_\_\_ for the treatment of melanoma. Mention that you will be asking your MLA to write a letter to the Minister of Health and Wellness about this issue and that you have with you a draft for their consideration.
3. Key Messages:
  - a. Melanoma is a life-threatening cancer of the melanocytes, cells that create melanin which control the color of your skin.
  - b. Medications are an important cornerstone of treatment for people with melanoma, and \_\_\_\_\_ is a new vital treatment that must be made accessible to patients in (your province)\_\_\_\_\_.
4. Tell your MLA a brief version of your personal story and the link you have to melanoma. Try to include the importance medications have played in your experience.
5. Core Facts – select and mention some of the core facts around melanoma – Fact Sheet
6. **Ask – I am asking you to write a letter to the Minister of Health and Wellness requesting that they immediately provide \_\_\_\_\_ as a choice to patients and their health care providers in \_\_\_\_\_ (prov) through public funding.**
7. Dialogue – press your MLA until they agree to write the letter and ask them if they would like a copy of the prepared draft you brought. Remember to ask to be copied on the letter that your MLA sends.
8. Conclusion – thank your MLA for their time and for agreeing to write the letter. Let them know that you will be following up in the coming days and weeks.

# Press Release - Oct 2017

## Canadian Cancer Patient Network Calls on Ministers of Health and Cancer Agencies to Lift the Veil of Secrecy on Committee That May Be Delaying or Restricting Access to New Cancer Drugs for Patients

NEWS PROVIDED BY

Collective Oncology Network for Exchange, Cancer Care Innovation, Treatment  
Access and Education

Oct 18, 2017, 18:00 ET

SHARE THIS ARTICLE



- CONECTed Shining a Spotlight on the Lack of Transparency When it Comes to Access to Cancer Treatments -

EDMONTON, Oct. 18, 2017 /CNW/ - With federal, provincial, and territorial health ministers meeting in Edmonton later this week, a Canadian cancer patient network is expressing its concern about the lack of transparency in the pan-Canadian review process that formalizes recommendations on the funding of cancer therapies on public drug plans.

[Read more](#)



# Opinion Editorials - Nov 2017

Dr. Xinni Song submitted to Ottawa Citizen

Dr. Scott Ernst submitted to London Free Press

Dr. Kerry Savage submission pending

Dr. Marcus Butler submission pending

Dr. Mike Smylie submission pending

## **Ernst: Life and death decisions made in dark**

Dr. Scott Ernst, Special to Postmedia Network  
Friday, December 1, 2017 8:31:31 EST PM



London Free Press, Dec 2017

[Read more](#)

# Government Meetings

October 2017 - Dr. Kim Critchley, Deputy Minister, Health & Wellness, Prince Edward Island

June 2017 - Michele Evans, Assistant Deputy Minister, Pharmaceutical & Supplementary Benefits Division

May 2017 - Honourable Sarah Hoffman, Alberta Health Minister

May 2017 - Federal meeting with MP Mark Warawa, MP Joël Lightbound, and MP Dr. Colin Carrie in Ottawa

April 2017 - Kevin Wilson, Executive Director, Drug Plan and Extended Benefits Branch Saskatchewan Health Ministry

April 2017 - Jim Billington, Ministerial Assistant to the Honourable Jim Reiter, Minister of Health Saskatchewan Health Ministry, Government of Saskatchewan

March 2017 - Suzanne McGurn, Assistant Deputy Minister and Executive Officer, Ontario Public Drug Programs

February 2017 - Dr. Ian Rongve, Assistant Deputy Minister of Diagnostic and Clinical Services, Ministry of Health - British Columbia

February 2017 - Brendan Abbott, Executive Director, Acute and Provincial Services at BC Ministry of Health

February 2017 - Barbara Walman, Assistant Deputy Minister, Medical Beneficiary and Pharmaceutical Services Division

December 2016 - Dr. Ian Rongve, Minister of Health and Long-Term Care, and Brendan Abbott, Executive Director, Acute and Provincial Services at BC Ministry of Health