

save your skin
FOUNDATION



LA FONDATION
sauve ta peau

2021 Annual Report

January – December 2021
End of Year Report on
Foundation Activity & Achievements
www.saveyourskin.ca

About the Foundation

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 across Canada.

SYSF provides a community of oncology patient and caregiver support throughout the entire continuum of care, from prevention and diagnosis to survivorship.

“Kathy started off as a patient I was trying to save and ended up being someone who dedicates her life to helping to save others. The difference Save Your Skin has made in the lives of patients across Canada is immense.”



Dr. Michael Smylie
Medical Oncologist,
Cross Cancer Institute,
Edmonton, Alberta

Vision:

A Canada where skin cancer is prevented, survived and cured.

Mission:

Providing compassionate care and support to those touched by the disease while leading the fight against skin cancer through nationwide advocacy, education, and awareness.

Mandate:

To apply our leadership, expertise and mentorship to ensure equal, timely, appropriate, affordable access to skin and other cancers



Jimmy Turcotte

Ocular Melanoma patient

"In my bad luck I am extremely lucky to have met you. "Save Your Skin" is like an angel from heaven to help me keep hope and stay strong for my family".

The Cause

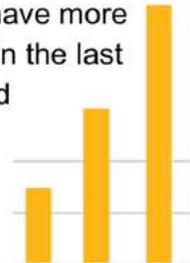


Melanoma is the most common form of cancer for young adults.

1,200

Over 1,200 Canadians will die from melanoma every year.

In Canada, incidences of melanoma have more than tripled in the last 30 years and continue to rise.



“Somebody finally seemed to know what they were doing. Where everything had been negative up to that point, Save Your Skin gave me something positive to hold onto. They’ve given me a new life. It if wasn’t for Save Your Skin, I wouldn’t be here.”



Mike Allan
Melanoma Survivor

Who are we reaching?

Save Your Skin Foundation reaches a variety of stakeholders including patients and caregivers, medical professionals, health professionals, industry and more. We speak and relate to those who want to make a real difference and who 'get' that sun safety is important for everyone.

How are we making a difference?

Save Your Skin Foundation is first and foremost an advocate for patients with skin cancer. We offer clear, qualified information about the disease, direct patients to reliable sources for more information and help patients access the medical and financial support they need to navigate their journey. We can do all of this because of the support of people like you. We rely on the support of our corporate partners and sponsors to sustain our much needed programs and initiatives.



2021 Priorities:

Prevention, screening and care to improve cancer outcomes. Engage Canadians to take a stand against skin cancer.

- Ensure equal, timely, appropriate and affordable access to the highest level of available therapies for patients and medical professionals
- Represent and inform the patient voice
- Increase investment against skin cancer
- Help shape health policy
- Be part of a solution for a sustainable health care system

Priorities achieved through:

- **Government Relations and Advocacy**
- **Education and Awareness**
- **Patient Support and Survivorship**
- **Fundraising and Events**
- **Marketing and Communications**



HIGHLIGHTS

Government Relations and Advocacy

SYSF Endorses the Declaration of Personal Health Data Rights in Canada

Developed by a patient and caregiver-led Data Working Group formed from the annual Patients Redefining the Future of Healthcare in Canada Summit, the Declaration of Personal Health Data Rights in Canada is intended to create greater consensus on the fundamental principles associated with personal health data, particularly from the perspective of patient and citizen groups; in order to encourage the health ecosystem to work out how to achieve these principles efficiently and effectively in partnership with industry, policy-makers, other data custodians, and patients. [READ MORE](#)

Endorsements as of June 14, 2021

Organizations

- HeartLife FOUNDATION
- badgut.org
- Canadian Spondylitis Association
- Demelio Partners
- Alma Canada (Al paraiso)
- PSORIASIS
- hpv vph global action
- lung health foundation
- amiQuébec
- REXNIHL breast cancer
- MIT
- MON
- CCRCN
- RISCC
- The Life Raft
- Canadian NeuroInfectious Disease Society
- MYELOMA CANADA
- MYELOMA CANADA
- SSC+
- SCS+
- ALL CAN CANCER
- LE COSS CANADIEN DES AVANGÉS

Individuals

- Alan Huang, Vancouver, British Columbia
- Alice Mayhew, Toronto, Ontario
- Amy Ma, Montreal, Quebec
- Andreea Redway, Ottawa, Ontario
- Gilles Caron, Mont-Tremblant, Quebec
- John Swedon, Whitby, Ontario
- Margaret Eysenbaum, Brampton, Ontario
- Michael Eysenbaum, Brampton, Ontario
- Robin Sully, Ottawa, Ontario

PATIENTS REDEFINING THE FUTURE OF HEALTHCARE IN CANADA

Executive Summary

P. 3

EXECUTIVE SUMMARY: Declaration of Personal Health Data Rights In Canada

People own their personal health data while custodians of that data own the records. Since people own their personal health data, they have corresponding rights over the personal health data they provide.

Declaration of Personal Health Data Rights in Canada

- 1 Right to be informed:** Individuals have the right to formal notice prior to the collection of their personal health data. Individuals have the right to be informed, using concise, accessible, plain language, about how a custodian will be processing or commercializing their personal health data.
- 2 Right to consent:** Individuals have the right to consent, and withdraw consent, to the processing or commercialization of their personal health data. Different intended purposes require different degrees of consent, either implied consent or express consent, including health care provision and the circle of care; research for public benefits using de-identified data; research using identifiable data; and commercial purposes.
- 3 Right to access, portability & correction:** Individuals have the right to request a portable copy of the personal health data they provided to a custodian and to the correction of their data where they identify inaccuracies. Individuals have the right to receive their data in a structured, commonly used, machine-readable format at no cost. For individuals without digital devices and/or internet, timely access will be provided to them in another format (e.g. hard copy) ideally at no cost.
- 4 Right to de-identification:** Whenever feasible and reasonable, individuals have the right for their personal health data to be de-identified prior to its being shared with anyone other than themselves or their circle of care for purposes for which they have given informed consent.

PATIENTS REDEFINING THE FUTURE OF HEALTHCARE IN CANADA

Executive Summary

P. 1

EXECUTIVE SUMMARY: Declaration of Personal Health Data Rights In Canada

- 5 Right to benefit:** Individuals have the right to benefit from their personal health data, including from their data being processed or shared for research or any other purpose. In order to benefit, patients recognize the importance of sharing their personal health data, while recognizing custodians' duty to respect, protect, and fulfill personal health data rights.
- 6 Right to object to processing:** Individuals have the right to object to the non-care related processing of their personal health data, such as processing for direct marketing.
- 7 Right to restrict processing:** Individuals have the right to restrict the processing of personal health data in specific situations, such as where the individual contests the accuracy of the data, or where the individual has objected to the processing of their data and is awaiting the decision of a complaint.
- 8 Right to a complaint process:** Individuals have the right to a complaint process by their data protection authority if they believe the processing or commercialization of their personal health data violates legislation.
- 9 Right to privacy and security:** Individuals have a right to have their personal health data processed in a way that meets current standards and regulations of privacy and security.
- 10 Right to erasure:** Individuals have the right to request that their personal health data be erased, which is sometimes called the right to be forgotten. This right only applies in certain specific circumstances, such as where the data are no longer necessary for the purpose(s) for which they were processed.
- 11 Right to engagement:** Patients, and their caregivers, have the right to be part of decision-making related to personal health data to ensure their views, perspectives, and values are meaningfully incorporated into decision-making processes.

PATIENTS REDEFINING THE FUTURE OF HEALTHCARE IN CANADA

Executive Summary

P. 2

COVID-19's Echo Pandemics – The Way Forward, the 6th Annual Patients Redefining the Future of Health Care in Canada Summit

This year's Summit built on the themes from last year, including exploring the ongoing barriers and systemic issues in the health system experienced by patients in Canada that have become starkly clear in light of the COVID-19 pandemic. The Summit focused on the current state of health care with particular focus on the "echo pandemics", in particular for Indigenous communities as well as specific patient communities including chronic disease, oncology, and mental health, while looking at how equity and health data support our ways forward.

READ MORE

PATIENTS REDEFINING THE FUTURE OF HEALTH CARE IN CANADA

SAVE YOUR SKIN FOUNDATION
Always in action. Always for you.

SAVE THE DATES

6th Annual Patients Redefining the Future of Health Care in Canada Summit & Webinar Series

PRE-SUMMIT WEBINAR SERIES

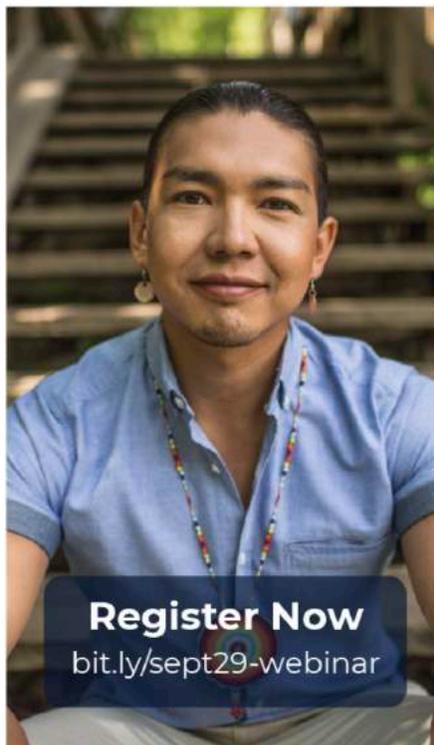
Webinars on the Determinants of Health
Late June and Early September 2021

Governments' Responsibilities in Health, including Determinants of Health
Late September 2021

Where We've Been & Where We're Headed: Patients Redefining the Future of Health Care in Canada Summit
Early October 2021

6TH ANNUAL SUMMIT

Patients Redefining the Future of Health Care in Canada: COVID-19's Echo Pandemics—the Way Forward
Week of November 15, 2021



Register Now
bit.ly/sept29-webinar

SAVE THE DATE

6th Annual Patients Redefining the Future of Health Care in Canada Presents:

Indigenous Social Determinants of Health: Impact of COVID-19

Presented by Dr. James Makokis

SEPT. 29, 2021 | 3 PM ET | 12 PM PT

Indspire

rivers to success
Monitoring Indigenous Students

PATIENTS REDEFINING THE FUTURE OF HEALTH CARE IN CANADA

save your skin FOUNDATION

saveyourskin.ca

Canadian Psoriasis Network

Réseau canadien du psoriasis

WEBINAR

Developed and deployed **#4weeksnot4months** campaign including Op-Ed in Globe & Mail to PM and Premiers and letters to MPs and MPPs

Succeeded in prompting 5 provinces and NACI to change their Guidelines for vaccine roll out for immuno-compromised people.

READ MORE

Signatories:



Open letter to the Prime Minister of Canada and the Provincial and Territorial Premiers. We need your help!

From Concerned Cancer Patients and their Patient Group Representatives

Urgent changes needed.



For COVID-19 vaccines to provide the best protection against the virus for cancer patients, the COVID-19 vaccine rollout across Canada MUST CHANGE URGENTLY.

As cancer patients, family members and oncology patient group representatives, we call upon the Federal, Provincial and Territorial governments to rollout the COVID-19 vaccines to cancer patients across Canada according to **best clinical trial evidence** and the **advice of their doctors**.

That means receiving the first and second doses of the available COVID-19 within 21 – 28 days.

Findings from recent studies show that the immune response that occurs after the first dose of the COVID-19 vaccine in seniors¹ and cancer patients² is reduced compared to the response in healthy individuals, leaving these individuals vulnerable without their second dose. Waiting up to four months between first and second doses leaves cancer patients at greater risk of **inadequate** defence against COVID-19.

Cancer Patients Are Asking ALL LEVELS OF GOVERNMENT TO HELP!

It is imperative that changes be made.

The present rollout recommendations and practices of up to **4 months** between the first and second doses has the potential to put the lives of cancer patients in jeopardy.

Patients are calling on the Federal and Provincial/Territorial governments, including local administrators, to protect those who are amongst the most vulnerable.

Up to 4 weeks between vaccine doses for cancer patients, NOT 4 months. #4weeksnot4months

Federal Government:

Revise the National Advisory Committee on Immunization (NACI) recommendation for cancer patients to receive the 2 doses of the vaccines within 21 –28 days of each other, as approved by Health Canada.

Provincial and Territorial Governments Including Local Administrators:

Ensure that the roll-out of the COVID-19 vaccines for cancer patients for the first and second doses is within 21 – 28 days of each other. Ensure adequate directives and resources are provided to achieve this goal.

To learn more, visit: VaccineAction.ca

BY-MONTH

Government Relations and Advocacy

JANUARY

Sent letters to federal and provincial health bureaucrats regarding vaccine roll out activities

Attended Canadian Mental Health Commission Think Tank

FEBRUARY

Met with federal Assistant Deputy Minister of Health to discuss plans for Canada Drug agency

MARCH

Presented on Canada-America Business council panel re: development of Resilient Healthcare systems

APRIL

Developed materials for #4weeksnot4months campaign including Op-Ed in Globe & Mail to PM and Premiers and letters to MPs and MPPs

MAY

Succeeded in promoting #4weeksnot4months campaign, resulting in 5 provinces and NACI changing their Guidelines for vaccine roll out for immuno-compromised people

Held call with BC Health Critic regarding COVID-19 second vaccines for vulnerable cancer patients

Co-developed a pan-Canadian vaccine roll out campaign for oncology patients including NACI, health ministries, and public health agencies

Attended Northwinds meeting on the future of healthcare

Reviewed GMEP by PMPRB and attended PMPRB public consultation

Attended federal Open Dialogue on AI in Canada

JUNE

Published Declaration of Data Rights

Hosted Webinar: "Social Determinants of Health" in lead up to Patient Summit

Presented webinar introducing Business Case for Optimizing Immuno-Oncology

Distributed letter of recommendations to overhaul NACI to PHAC, HC, federal & provincial Ministers and ministries of health with fellow patient groups

Sent submission for GMEP consultation to PMPRB with fellow patient groups

Met with Dr. Bill Evans and Dr. Kelvin Chan and other patient representatives to discuss CanREValue consultation with patient groups regarding patient engagement

JULY

Met with consultant from Santis to provide feedback on Canada Drug Agency

Held call with Health Canada to discuss submission for GMEP consultation by PMPRB

Met with Canada Health Infoway to review results of its digital literacy project survey and provide advice

AUGUST

Presented at BeiGene regarding Lymphoma White paper recommendations

Presented on Resilient Healthcare Coalition Podcast

Met with patient advocacy groups to develop tactics for federal election for oncology patient groups; developed letter for candidates for patient groups/patients to send

Co-created 'Make Healthcare a priority' campaign to enable people to send their local federal candidates a letter using a simple, automated website

Created and launched survey for pCODR submission: "The Patient Experience: Surgical and Systemic Treatment of Advanced Basal Cell Carcinoma and Squamous Cell Carcinoma" in English and French

Met with National Advisory Committee on Immunization (NACI) to discuss patient group recommendations to enhance NACI Terms of Reference

Met with Canada Health Infoway to review results of digital literacy project survey

Assisted CanREValue consultation regarding patient engagement and attended first consultation

Attended meeting with medical researchers interested in mental health, prostate cancer and Indigenous community engagement

Met with BioCanRx representative to discuss letter of support from CSA for patient engagement in basic science research; prepared letter of support

Meet with Quebec colleagues to discuss issues relevant to Quebec including VBHC study; federal election; healthcare issues including INESSS

Held discussions with EMPaCT to develop tactics for presentation oncology specific EMPaCT group inclusion

SEPTEMBER

Held call with Physicians and pharmaceutical partners to discuss issues in ocular melanoma patient special access to treatment

Attended Resilient Healthcare Committee meeting to discuss election and plan next steps

Developed OpEd and panels with fellow patient groups to coincide with the 2021 Council of Federation meeting

Sent NACI copy of patient group recommendations to enhance NACI Terms of Reference

Attended Canada Health Infoway consultation on expansion of PrescribeIT project for e-prescribing

Completed and distributed letter of support to CSA for patient engagement in BioCanRx supported basic science research project

Met with BioCanRx and Dr. Chan to discuss BioCanRx public forum

Provided interview to international C Difficile group regarding issues of diagnosis and treatment of C Difficile in Canada

Attended NHC/Tufts/UMB meeting to advise on a project regarding the development of a patient-centred generic value assessment tool

Attended EU patient summit on data issues

OCTOBER

Completed OpEd to coincide with the 2021 Council of Federation meeting

Attended BC Sun Safety and Ontario Sun Safety meetings

Attended Canadian Jurisdictional Roles in Health & Determinants of Health meeting

Attended Resilient Healthcare Committee meeting to discuss election, distributed

Distributed RHC "Joint Mandate letter" to Ministers of Health and Innovation to patient groups for endorsement

Attended Canadian Cancer Society Advocacy Roundtable

Attended Santis Consultants Election webinar

Attended 2nd CanREValue patient consultation meeting

Attended PHAC Consultation regarding National Data Management Strategy

Attended Conference Board Value Based Health Care management meeting

Attended CADTH workshop on moving from HTA to HTM

NOVEMBER

Attended Walrus Leadership roundtable

Attended Resilient Healthcare Committee meeting

Attended Canada Infoway e-prescribing (PrescribeIT) expansion consultation

Held meeting with Conference Board lead on Value-Based Health Care projects

DECEMBER

Attended CAHR Conference on access issues

Attended CADTH workshop on Technology Trends to Watch in 2022-2024

Reviewed PMPRB Regulation delay notification and decision regarding “Gaps and Grandfathering” shared with patient groups

Met with NRC representative to discuss health policy issues

Met with Canada Drug Agency representatives to discuss mandate for CDA and patient engagement

Reviewed Resilient Healthcare Coalition materials and attended RHC meeting

Met with Ottawa Hospital doctors re: doctors’ experience with virtual care

Met with Linda Wilhelm and Robyn Lim, co-authors of Patient Treatment Decision Guide to discuss updating and disseminating Guide for 2022

Prepared letter regarding reimbursement of eye cancer drugs in B.C.

Provided input to international patient groups GOAL regarding potential international oncology project regarding delays in diagnosis

HIGHLIGHTS

Education and Awareness

250

Registrants

114

Attendees

618

Recording
views

[WATCH HERE](#)

WEBINAR save your skin FOUNDATION LA FONDATION sauve ta peau

MELANOMA & NON-MELANOMA SKIN CANCERS FROM A - Z

13 May 2021 | 11am PT / 12pm MT / 2pm ET

Join us to learn everything you need to know about skin cancers from prevention and early detection to navigating treatment options and living with a diagnosis

Presenter: Thomas G. Salopek, MD FRCPC, Professor, Department of Medicine, Division of Dermatology, University of Alberta

LA ROCHE POSAY LABORATOIRE DERMATOLOGIQUE Quebec Cancer Foundation ASM Alberta Society of Melanoma f t i saveyourskin.ca

106

Registrants

45

Attendees

740

Recording
views

[WATCH HERE](#)

Post-ASCO Update with Dr. Hamid WEBINAR
Non-Melanoma Skin Cancers,
Melanoma, and Ocular Melanoma

Tues, June 15, 2021 - 5pm PT / 8pm ET

Get key medical insights on new treatments and research presented at the American Society of Clinical Oncology (ASCO) Annual Meeting in early June 2021, including recent announcements on immunotherapies and targeted therapies for adjuvant and metastatic melanoma, squamous cell carcinoma, basal cell carcinoma and ocular melanoma.

Presented by Dr. Omid Hamid, The Angeles Clinic and Research Institute, Los Angeles, California.

[Click here to register](#)

Proclamation Initiative

Save your Skin Foundation's Proclamation Initiative invites Canadian municipalities to take a stance against skin cancer and educate their communities on sun safety through mayoral proclamations.

50 municipalities
10 provinces

In 2021, thanks to our outreach efforts 50 municipalities in 10 provinces across Canada issued signed Proclamations to proclaim the month of May 2021 'Melanoma and Skin Cancer Awareness Month'. [READ MORE](#)



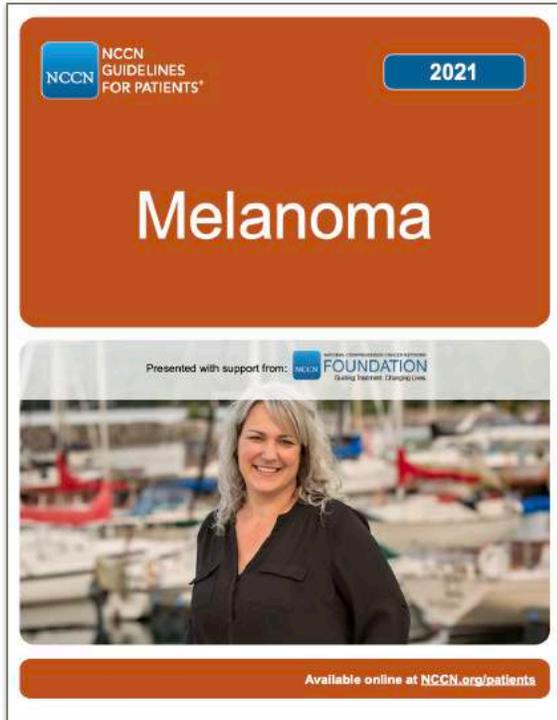
Virtual Care Guide & Appointment Planner

Tools developed to help people connect with Health care professionals virtually and get the most out of virtual appointments. [READ MORE](#)

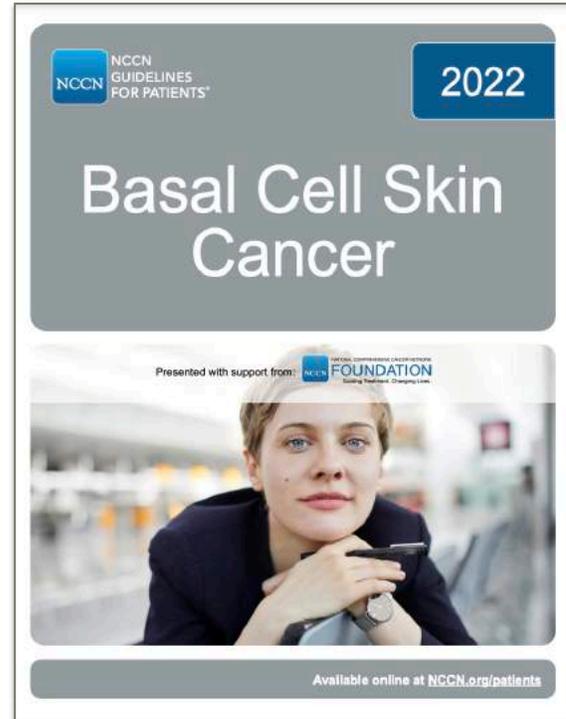


SYSF provided endorsement to the updated Melanoma and brand new Basal Cell Skin Cancer NCCN Patient Guidelines, with our Managing Director being featured on the cover of the Melanoma guide:

- **Melanoma**



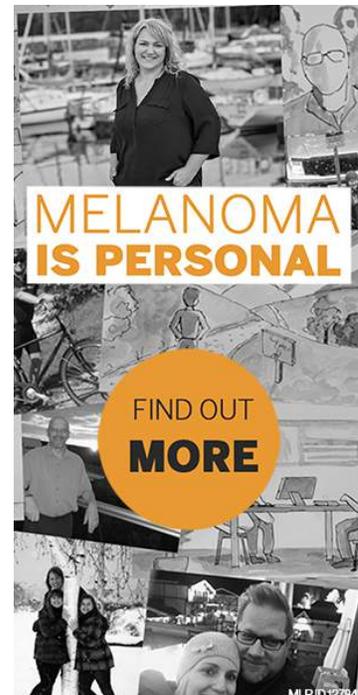
- **Basal Cell Skin Cancer**



#InItTogether Campaign - Melanoma is Personal

Patients, Survivors, and Caregivers from the Save Your Skin Foundation family have come together share their story to inspire education and hope.

[Watch the 'In it Together' video on our blog](#)



Skin colour chart for skin cancer risk developed during Black History Month

Skin colour chart for UV sensitivity and skin cancer risk							save your skin FOUNDATION  LA FONDATION sauvé ta peau
Natural skin colour	Very pale, white, often freckled 	Fair, white 	Medium, white to olive brown 	Olive to moderate brown 	Medium brown to dark brown 	Very dark brown to black 	
UV sensitivity & tendency to burn	Extremely sensitive Always burns, never tans	Very sensitive Burns easily, tans minimally	Sensitive Burns moderately, usually tans	Less sensitive Burns minimally, tans	Minimal sensitivity Rarely burns	Minimal sensitivity Never burns	
Skin cancer risk	Greatest risk of skin cancer	High risk of skin cancer	High risk of skin cancer	At risk of skin cancer	Less risk of skin cancer, but when diagnosed it is often at a later stage.	Less risk of skin cancer, but when diagnosed it is often at a later stage.	

SOURCE: The Fitzpatrick scale

SURVEY REPORT

“The Continued Affects of COVID-19 on Melanoma, Ocular Melanoma, and Non-melanoma Skin Cancer Patients”

COVID-19 Patient Impact Survey – 2021

In follow up of our COVID-19 Impact Survey of April 2020, we ran a second survey from Jan – Feb 2021 to assess the continued impact of the pandemic on the medical needs of patients with melanoma, ocular melanoma, and non-melanoma skin cancer. [READ MORE](#)

Save Your Skin Foundation launched the STY-LIVES program to empower and educate Canadian hair stylists and barbers to detect suspicious spots on the heads and scalps of their clients. Led by medical students, the program is the first of its kind and aims to increase early detection. [READ MORE](#)



BY-MONTH

Education and Awareness

JANUARY

Co-hosted and presented at Day 1 of the patient education session on pCODR submissions with Martine Elias

Coordinated dissemination of Report Back from 2020 Summit

Launched COVID-19 Impact Survey (FR & EN)

Created new Skin Check Guide page and downloadable materials (EN & FR)

FEBRUARY

Presented at S2BN panel on patient engagement

MARCH

Announced Resource Partnership with BC Lymphedema Association

APRIL

Coordinated a Canada-wide May Proclamation initiative, liaising with municipalities across Canada to declare May as Melanoma Month

Coordinated Melanoma Awareness Month initiatives with Atlas, Spectrum, AIM at Melanoma, Melanoma Research Foundation, and Canadian Skin Patient Alliance

MAY

Hosted Webinar: "Melanoma & NMSCs From A-Z" with Dr. Salopek

Gave Melanoma Awareness Month/Sun Safety presentation to New Westminster Council

Developed and circulated Virtual Care Guide and Checklist and created web pages, in English and French

Sent thank you letters and Sun Safety Awareness packages to all municipalities who participated in the proclamations initiative

JUNE

Hosted Webinar: "Post-ASCO 2021" with Dr. Hamid

AUGUST

Created brochures in English and French for upcoming STY-LIVES project

SEPTEMBER

Created How to Find a Dermatologist page on website

OCTOBER

Confirmed partnership with BCDO and AAO for 2021 #EyeGetDilated campaign

Supported and endorsed launch of new NCCN Patient Guide for BCC

NOVEMBER

Hosted Webinar on AI: The Future of Healthcare – Just Because We Can, Doesn't Always Mean We Should

Ran digital #EyeGetDilated campaign for Ocular Melanoma Awareness

Coordinated meetings with AAO & BCDO for collaboration on #EyeGetDilated campaign

Launched Skinopathy/GetSkinHelp partnership and featured YouTube Live event

Prepared plan for using the Leger Survey Results in 2022

DECEMBER

Launched Sty-Lives (Styling Hair & Saving Lives) project including providing volunteers with print resources, onboarding salons, coordinating digital launch and deploying press release

Launched newly updated SYSF website

Created a Holiday Letter recapping SYSF top achievements in 2021 for patients and sponsors (EN & FR)

HIGHLIGHTS

Patient Support and Survivorship

Hosted monthly patient support chats



1st Thursday of every month
Join for free on your phone or online anywhere you have wifi

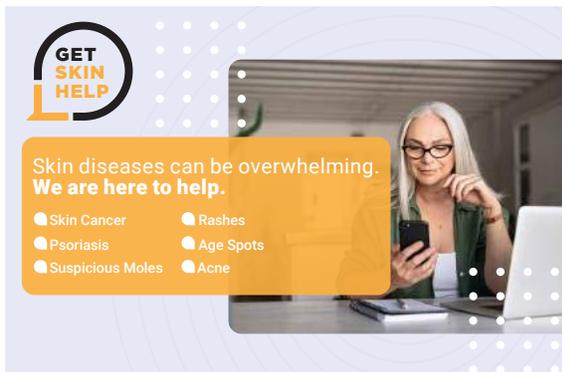


5pm PST
8pm EST
9pm AST

Provided endorsements to NCCN Patient Guidelines:

- Survivorship Care for Healthy Living
- Survivorship Care for Cancer-Related Late and Long-Term Effects

[READ MORE](#)



GET SKIN HELP

Skin diseases can be overwhelming. We are here to help.

- Skin Cancer
- Psoriasis
- Suspicious Moles
- Rashes
- Age Spots
- Acne

Save Your Skin partnered with Skinopathy for the launch of the #GetSkinHelp app

The free #GetSkinHelp app uses SkinAI™ technology to users' assess skin concerns and connect them with a skin doctor virtually.

[READ MORE](#)

Hosted Ocular Melanoma Task Force Canada meetings

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



Updating the Ocular Melanoma Care Landscape in Canada

Survey Report by Ocumel Canada,
an initiative of Save Your Skin Foundation
July 2021

Ocumel Canada launched the “Updating the OM Care Landscape in Canada” **Patient Survey** and corresponding report to help bring awareness to Ocular Melanoma (OM) and improve care pathways for patients across Canada.

READ MORE

Hosted a virtual **Holiday Party** to connect with our community of patients, caregivers, friends and supporters



Join our Virtual
Holiday Party

HOSTED BY SAVE YOUR SKIN FOUNDATION

DECEMBER | **5PM PT** | FOR ALL PATIENTS,
19TH | **8PM ET** | FAMILY MEMBERS
& FRIENDS! **xoxo**

Created new Patient Support contact card for distribution through Physicians offices & clinics



save your skin FOUNDATION LA FONDATION sauve ta peau

Committed to providing compassionate support for all Canadians living with skin cancer

MIKE, Stage 4 melanoma survivor
They've given me a new life. If it wasn't for Save Your Skin, I wouldn't be here.

You're not alone in your cancer battle, Save Your Skin is an amazing resource for information and support.
VIOLETTA, Melanoma survivor

It's not that I think Save Your Skin Foundation saves lives, I know that it does.
NIGEL, Ocular melanoma patient

saveyourskin.ca ASM Alberta Society of Melanoma



Hand in Hand, We Fight Skin Cancer Together

Save Your Skin Foundation was founded in 2006 by melanoma survivor Kathleen Barnard. We provide support to patients and caregivers touched by melanoma, non-melanoma skin cancer, or ocular melanoma and we help find information about treatment options. Find us at newlydiagnosed.saveyourskin.ca

JOIN OUR MONTHLY SUPPORT CHATS, VISIT US ONLINE AT SAVEYOURSKIN.CA, OR CALL US AT 1-800-460-5832 TO LEARN MORE

Held on the first Thursday evening of each month, our patient support chats are available by phone or computer, for informal, open discussions about life after diagnosis. Family and caregivers welcome. Visit bit.ly/systchat.

GET SOCIAL WITH US:
@saveyourskinfoundation @saveyourskinfdn @saveyourskinfdn

JOIN OUR ONLINE SUPPORT GROUPS

We run two private groups on Facebook for patients to connect with fellow patients, survivors, and caregivers:

Melanoma and Skin Cancer Connect - facebook.com/groups/melanomacconnect
Ocular Melanoma Connect - facebook.com/groups/ocularmelanomacconnect

If you or someone you know has been touched by skin cancer and is in need of assistance, please reach out to us at 1-800-460-5832 or kathy@saveyourskin.ca.

[View our downloadable resources HERE](#)

Conducted a Patient Experience Survey for Non-Melanoma Skin Cancer patients to inform Save Your Skin Foundation's recommendations to CADTH and pCODR



THE PATIENT EXPERIENCE
Survey for non-melanoma skin cancer patients



BY-MONTH

Patient Support and Survivorship

JANUARY

Hosted January patient support chat

Provided endorsement for New NCCN Guidelines: Survivorship

FEBRUARY

Hosted February patient support chat

Provided endorsement for new NCCN Guidelines for Basal Cell Carcinoma

MARCH

Hosted March patient support chat

Created new SYSF Patient support post card

Worked with MNC to design co-branded Adjuvant Resource for patients

APRIL

Hosted April patient support chat

Launched Ocumel Canada Patient Survey “Updating the OM Care Landscape in Canada”

MAY

Hosted May Patient Support Chat

Hosted Ocular Melanoma Task Force Canada meeting

JUNE

Hosted June patient support chat

Coordinated/facilitated merger with Alberta Society of Melanoma

Held 2021-2022 partnership meeting with Quebec Cancer Foundation

Held meeting with GetSkinHelp

JULY

Hosted July patient support chat

Oversaw the creation of training video for upcoming STY-LIVES project

AUGUST

Held meeting with Castle Biosciences re: OM and Cutaneous Melanoma collaboration

Released Ocumel Canada Report: Updating the Ocular Melanoma Care Landscape in Canada

SEPTEMBER

Hosted Physician Roundtable, Kelowna, BC

Hosted monthly Patient Support Group Chat

Hosted Melanoma/NMSC/OM Patient/Caregiver Roundtable

Held call with Zamplo, preparation for creating a Community

OCTOBER

Hosted October patient support chat

Held meetings with GetSkinHelp/Skinopathy re: webinar

Hosted Ocular Melanoma Task Force Canada Physician's meeting

NOVEMBER

Hosted November Patient Support Chat

Responded to request for financial support from French patient

Held several patient support calls with patients

Purchased a Star for daughter of patient

Attended Adjuvant melanoma national consultation meeting

Attended Lung Cancer Canada patient consultation

Met with Look Good Feel Better

Had a meeting with CEPPP to discuss potential partnership

Met with President of company Data Equity to discuss potential opportunities for collaboration

DECEMBER

Hosted December Patient Support Chat

Held meetings with two QC patients who requested financial support

Hosted SYSF Holiday party in custom Topia world

Held meeting with Canadian Skin Cancer Foundation

HIGHLIGHTS

Fundraising and Events

Hosted A Viking's Challenge 2nd Edition fundraising event. [READ MORE](#)



64 Participants across Canada

855km run in total

\$9,000 raised

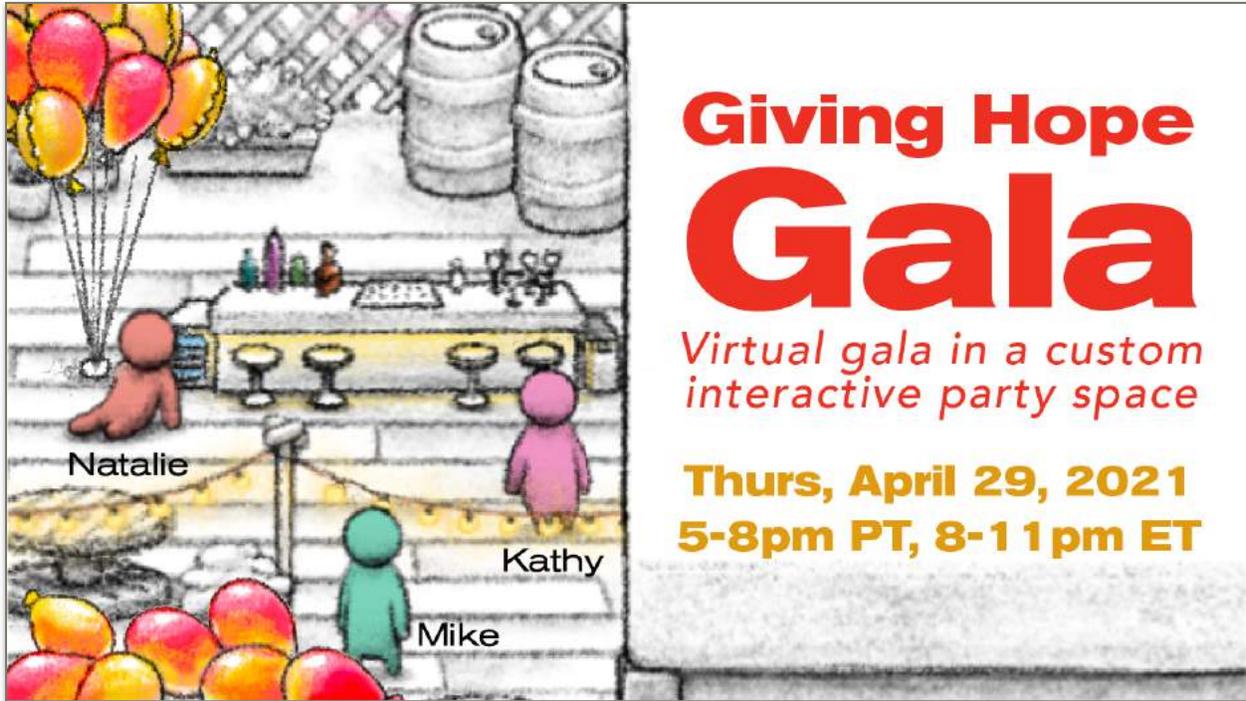
3 pieces media coverage



Vancouver Canucks' JT Miller and his wife Natalie joined SYSF as celebrity spokespeople

JT's Cameos **raised \$11,000** in 2021

and his voice helped raise the profile of Save Your Skin Foundation.



Giving Hope Gala

Virtual gala in a custom interactive party space

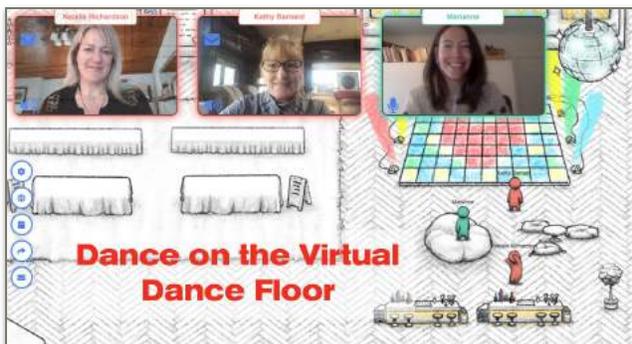
Thurs, April 29, 2021
5-8pm PT, 8-11pm ET

Save Your Skin's annual Giving Hope Gala went virtual this year, hosted in a custom interactive party space. Complete with a unique spatial video functionality, music, dancing, a photo booth and silent auction, this was THE virtual event of the season.

118 attendees

\$22,000 in net revenue from sales, donations and sponsorships

[READ MORE](#)



Save Your Skin Foundation's Signature Cocktail

TEQUILA STAY-OUT-OF-THE-SUN(RISE)

Ingredients

1 1/2 oz (3 parts) tequila or soda, 1/2 oz (1 part) grenadine syrup, 3 oz (6 parts) mango juice.

Preparation

Pour the tequila and mango juice into a glass over ice. Add the grenadine, which will sink to the bottom. Do not stir. Garnish and serve.

Served

On the rocks; poured over ice.

Standard garnish

A cherry, an orange slice, and an umbrella of course!

Drinkware

Collins glass





MOVE FOR MELANOMA

OCULAR MELANOMA & NON-MELANOMA SKIN CANCERS

ACROSS CANADA



SEPT. 25-26, 2021

Save Your Skin's annual Move For Melanoma event was hosted **virtually** again this year. The 2021 event saw the addition of a dedicated Ocumel Canada team and a special 'Train Like A Canuck' team that challenged participants to complete a typical Canucks workout. [READ MORE](#)

95 participants

\$68,520 in net revenue

86% from private donations

2 pieces media coverage



BY-MONTH

Fundraising and Events

JANUARY

Launched A Viking's Challenge fundraising event and registration platforms, began sponsorship outreach (new logo)

Designed A Viking's Challenged T-shirts and updated SYSF Merchandise Store

FEBRUARY

Welcomed new celebrity spokesperson Vancouver Canucks' JT Miller

MARCH

Hosted A Viking's Challenge 2021 fundraising event, raising \$9,000

Launched 2021 Giving Hope Gala event and ticketing page

APRIL

Hosted 2021 (virtual) Giving Hope Gala on April 29th with virtual silent auction

Created SYSF's 15th Anniversary Slideshow

JUNE

Created new merchandise in English and French including Stickers, T-shirts, Golf shirts and UV sleeves

JULY

Launched the 2021 Move For Melanoma fundraising event

Created and added new merchandise items to Etsy store

AUGUST

Launched 'Train Like A Canuck' activity challenge for Move For Melanoma 2021

Created Team Ocumel Canada strategy for Move for Melanoma

Hosted August Patient Support Group Chat

Added new story to I'm Living Proof map (in English and French)

SEPTEMBER

Hosted 3rd annual MOVE FOR MELANOMA fundraising event and raised over \$75,000

OCTOBER

Prepared and hosted booth at the Canadian Association of Nurses in Oncology (CANO) conference

NOVEMBER

Ran successful digital Giving Tuesday campaign resulting in over \$4,000 in donations

Liaised with two patients about fundraisers they are leading to benefit SYSF

DECEMBER

Updated CanadaHelps page with new testimonial

Prepared post-Summit report

Facebook photo frames



Melanoma Month T-shirts



BY-MONTH

Marketing and Communications

FEBRUARY

Published press release for A Viking's Challenge fundraising event

MARCH

Prepared and deployed Canada Health Transfer increases media release and released on newswire

Prepared and deployed BRAFTOVI and MEKTOVI Notice of Compliance media release

Developed and launched a SYSF's 15th anniversary communications plan, including dedicated logo, special T-shirt, commemorative video and social media content

Media outreach and management for A Viking's Challenge

APRIL

Drafted and deployed press release, "Save Your Skin Foundation Teams up with Vancouver Canucks' JT Miller to Spread Message of Sun Safety Amid Rising Skin Cancer Rates" on newswire, duplicated in French

Provided interview to Postmedia as background to story on vaccines

Created 3 new T-shirts designs for Melanoma Awareness Month and updated Etsy Store

MAY

Rolled out Melanoma Skin Cancer Month social media campaign in EN and FR

Drafted and distributed national Proclamations press release, as well as local press releases for each province

Began airing Spring/Summer Public Service Announcement on SHAW TV until August 31, 2021

Collaborated with MI-PAC, MRF Global Coalition for Melanoma Patient Advocacy, and Ocumel UK on Melanoma Month campaigns

Collaborated with Walmart Quebec to be part of the Access platform for month of May

Created and launched Facebook photo frames for summer

JUNE

Published press release for merger with Alberta Melanoma Society

Published media advisory for expected BC heatwave

Created Sun Safety Tips infographic

JULY

Launched 'Melanoma Is Personal - In It Together' campaign featuring videos of cancer care stakeholders, celebrity spokesperson Hayley Wickenheiser and articles in Elle Canada and VÉRO

AUGUST

Created promotional videos for Move For Melanoma 2021

SEPTEMBER

Deployed social media campaign and paid Facebook ads for Move For Melanoma

Published press release for Melanoma Month

Sent media pitches to local and media outlets for Move For Melanoma coverage

OCTOBER

Provided interview regarding impact on cancer patients of pandemic

Participated in World Sight Day, announced NCCN Basal Cell Guidelines, recruited for skin workshop, and promoted Patient Summit webinars

Created #EyeGetDilated campaign materials and patient stories

NOVEMBER

Provided interview to AIM at Melanoma

Deployed press release for Health Canada for Approval of Libtayo (Cemiplimab) for Locally Advanced Basal Cell Carcinoma (LaBCC)

Ran digital #EyeGetDilated campaign for Ocular Melanoma Awareness

Ran Digital Health Week campaign announcing partnerships with Skinopathy/GetSkinHelp and Canada Health Infoway

Provided interview regarding impact on the value of disaggregated data

DECEMBER

Drafted and deployed holiday card/letter to patients and sponsors

Supported Sty-Lives launch with social media campaign

Supported GetSkinHelp launch with social media campaign

Deployed press release for new STY-LIVES program

Quebec

In 2021, partnerships with **La Fondation québécoise du cancer** and **La Roche-Posay** helped us expand our work in the province of Quebec and reach more French-speaking patients.

WEBINAIRE save your skin FOUNDATION LA FONDATION SAUVE LA PEAU

LE CANCER DE LA PEAU MÉLANOME ET NON MÉLANOME DE A À Z

13 mai 2021 | 11h00 PT / 12h00 HNR / 14h00 ET

Rejoignez-vous à nous pour apprendre tout ce que vous devez savoir sur les cancers de la peau, de la prévention et de la détection précoce aux options de traitement et à la vie avec un diagnostic.

Présentateur: Thomas G. Salopek, MD FRCP(C), Professeur, Département de médecine, Division de dermatologie, Université de l'Alberta

Logos: LAROCHE-POSAY, Québec Cancer Foundation, ASM Alberta Society of Melanoma, sauvelapeau.ca

Kiosque à la Classique de golf des parcs industriels de Québec



Le soleil d'été est de retour, Magazine Véro



Mois du mélanome social media content for the Walmart group of Quebec pharmacies

Mai est le mois de la sensibilisation au mélanome et au cancer de la peau

ASUVE LA PEAU CA

A SYMÉTRIE
La forme est-elle irrégulière?

B BORDS
Les bords sont-ils irréguliers/dentelés?

C COULEUR
Plusieurs couleurs peuvent apparaître?

D DIAMÈTRE
Le nævus fait-il plus de 6mm?

E ÉVOLUTION
Le nævus a-t-il changé avec le temps?

Pour plus d'informations sur les signes et symptômes du cancer de la peau, consultez nos pharmaciens.

Mai est le mois de la sensibilisation au mélanome et au cancer de la peau

ASUVE LA PEAU CA

Comment procéder à l'examen:

Étape 1
Examinez votre cuir chevelu en utilisant un peigne pour séparer vos cheveux. Si vous n'avez pas beaucoup de cheveux, assurez-vous d'examiner très soigneusement tout votre cuir chevelu.

Étape 2
Examinez soigneusement votre visage, y compris votre nez, vos lèvres, votre bouche et vos oreilles. N'oubliez pas le dessus et l'arrière de vos oreilles.

Étape 3
Concentrez-vous ensuite sur votre cou, votre poitrine et votre torse. Si vous êtes une femme, assurez-vous d'examiner entre vos seins et en dessous de vos seins.

Global Partnerships

In collaboration with the **Global Coalition for Melanoma Patient Advocacy**, Save Your Skin Foundation participated in the making of a skin check awareness video for Melanoma Awareness Month 2021, featuring melanoma patients and caregivers from across the globe.



Save Your Skin Foundation is a member of **MI-PAC**, a coalition of organizations across the globe committed to reducing the global melanoma burden through education, advocacy, and collaboration.



Save Your Skin Foundation is also a member of **Global Oncology Advocacy Leaders (GOAL)**.



2021 Conferences, Meetings & Presentations

FEBRUARY

Attended 15th Annual Canadian Melanoma Conference (virtual)
Attended Melanoma Research Alliance Scientific Retreat (virtual)
Attended R.O.C.O annual meeting
Attended CADTH educational session and patient groups session
Ocumel Canada - CureOM Global meeting

MARCH

Attended Quebec Cancer Coalition annual meeting
Attended Resilient Healthcare Coalition meeting
Attended BioCanRx Scientific Programme Committee meeting

APRIL

Attended MI-PAC Capacity Meeting (virtual)
Attended 10th EADO World Congress of Melanoma (virtual)
Attended CAHR annual meeting
Co-Chaired Global CureOM Meeting, Ocumel Canada

MAY

Attended IMC meeting
Attended R.O.C.O meeting
Attended international OM coalition meeting
Attended All.Can Global Summit

JUNE

Attended ASCO (virtual sessions)
Attended IMC Virtual Policy Summit

JULY

Attended Janssen Advisory Board to discuss processes to support cancer patients impacted by COVID-19 pandemic

SEPTEMBER

Attended European Society for Medical Oncology (ESMO) Congress

Co-hosted Webinar: Indigenous Social Determinants of Health

Presented at BeiGene summit as part of panel on health systems access barriers

OCTOBER

Presented at National Comprehensive Cancer Network Advocacy Networking Event

Presented on Sharing Progress in Cancer Care webinar series

Presented 3rd Patient Summit webinar, "Canadian Health Systems structures and Social Determinants of Health"

Hosted Canadian Association of Nursing in Oncology workshop and hosted a virtual exhibition booth

Presented on panel at Market Access conference

Presented at Obesity Network workshop

Attended CureOM Global Science Meeting

Attended Society for Melanoma Research Congress

NOVEMBER

Hosted 6th Annual Patients Redefining the Future of Healthcare in Canada Summit virtually on November 15th, 17th and 19th

Presented at CARP panel on COVID and cancer

Co-chaired BioCanRx public forum with Dr. Kelvin Chan

Attended MRF Global Coalition for Melanoma Patient Advocacy annual meeting

Presented Ocumel Canada to MI-PAC group

Attended CureOM Patient and Caregiver Symposium

Attended CureOM "Ask the Expert" Presentation with Dr. Weis

Attended BioCanRx patient-researcher roundtable

Attended CADTH symposium

DECEMBER

Presented at GRYT oncology group Advocacy Exchange panel

Attended Astra-Zeneca Cancer Roadmap meeting

Attended Global Ocumel Group meeting

2021 Media

JANUARY

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

20 pieces of earned media

3 pieces of paid media

FEBRUARY

SKIN CANCER NON-PROFIT INVITES CANADIANS TO TAKE PART IN A VIKING'S CHALLENGE, North Shore News, Feb 24, 2021.

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

HAL'S HEADLINES, Winnipeg Sun, Feb 13, 2021.



Chris (left) of Abbotsford and friend Shawn Bjornson of Winnipeg ran 30 kilometres across Lake Winnipeg in 2020, raising \$20,000 for the Save Your Skin Foundation. This year's event is being held virtually and invites participation from the public.

Abbotsford cancer survivor holds virtual run fundraiser for Save Your Skin Foundation

MARCH

MEET THE PATIENTS: SHANNON GAUDETTE, Innovative Medicines Canada, March 3, 2021.

ABBOTSFORD CANCER SURVIVOR HOLDS VIRTUAL FUNDRAISER FOR SAVE YOUR SKIN FOUNDATION, Abbotsford News, March 5, 2021.

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

PREVENT & PROTECT YOUR SKIN FROM CANCER, Health Insight, March 11, 2021.



BUTTONS MADE WITH LOVE – LOCAL GIRL'S CREATIONS SUPPORT TWO ORGANIZATIONS, Winnipeg Free Press, March 16, 2021.

APRIL

MORE OUTDOOR ACTIVITY INCREASING RISK OF SKIN CANCER, Radio Canada International, April 28, 2021.



During the pandemic, people are spending more time outdoors increasing their exposure to the sun and their risk of developing skin cancer. (iStock)

More outdoor activity increasing risk of skin cancer

CANUCKS' JT MILLER PARTNERS WITH CHARITY TO PROMOTE SKIN CANCER AWARENESS, C-FAX 1070, April 28, 2021.

MAY

REAL PATIENTS SPEAK: METASTATIC MELANOMA, Canadian Health and Family on CTV, May 10, 2021.

VANCOUVER CANUCKS PLAYER HELPS RAISE AWARENESS ABOUT SKIN CANCER, CTV News, May 13, 2021.

NEW WEST RESIDENTS URGED TO PLAY IT SAFE IN THE SUN, New Westminster Record, May 14, 2021.

MELANOMA AWARENESS MONTH: WHY YOU SHOULD WEAR SUNSCREEN EVERY DAY, Fleurish with Fleur, May 18, 2021.

JUNE

UBC DERMATOLOGIST SHEDS LIGHT ON SUNSCREEN MISCONCEPTIONS, CityNews, June 23, 2021.

RECORD-BREAKING TEMPERATURES EXPECTED UNTIL AT LEAST TUESDAY, Times Colonist, June 25, 2021.

JULY

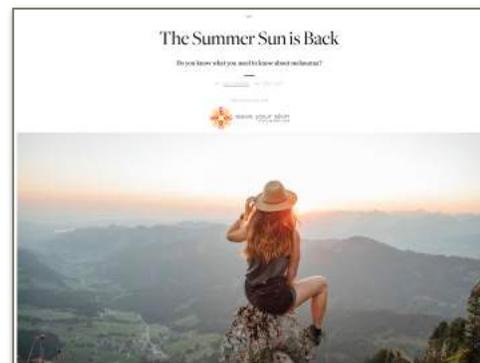
THE SUMMER SUN IS BACK, Elle Canada, July 13, 2021.

LE SOLEIL D'ÉTÉE EST DE RETOUR, Véro, 13 juillet 2021.

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

SEPTEMBER

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.

DECEMBER

DIFFERENTIATING BETWEEN NON-MELANOMA SKIN CANCERS, Health Insight, Dec 1, 2021.

TWO NORTHERN ONT. MED STUDENTS LEADING NATIONAL SKIN CANCER DETECTION PROGRAM, CTV Northern Ontario, Dec 8, 2021.

Family team to throw axes for six hours to support member and other patients battling cancer

Move for Melanoma brings awareness of skin and ocular cancers and raise funds

Sep. 17, 2021 10:30 a.m. / COMMUNITY



The small but mighty Laurence B. 'For Life' Team is participating in the third annual Move for Melanoma 2021 event to raise funds to support Laurence Butler and all the others living with melanoma, non-melanoma skin cancer and ocular melanoma across Canada.

In 2018, Butler discovered and was treated for a tumor behind his right eye. It was quite quickly determined to be metastatic uveal melanoma, a rare and deadly cancer. Since that

Differentiating between Non-Melanoma Skin Cancers



Thank you to our 2021 Sponsors

