

Immuno-Oncology Network for Patient Organizations

Patient Lead Education Summit 2017

Event Report Summary

Introduction

On Friday, March 31 and Saturday, April 1, 2017, the Immuno-Oncology Network for Patient Organizations (henceforth referred to as 'The Network') hosted the Patient Leader Education Summit (PLES). This was the inaugural meeting of The Network, and in attendance were health technology assessment professionals, medical professionals, and patient advocacy leaders from several cancer indications. The Network's goals are to unify the patient voice and empower patients and advocates to be fully engaged in healthcare decision-making, to work in tandem with all the stakeholders involved towards solutions for a sustainable system, and to ensure that cancer patients have access to cancer therapies. The Network will be devoted to ensuring that the system remains sustainable for cancer care, and it is committed to increasing innovation and research in Canada, while expanding access to new therapies within a dynamic regulatory framework that is dedicated to improving cancer care across all therapies and tumour sites.

Steering Committee

The steering committee of the Immuno-Oncology Network for Patient Organizations consists of:

Kathleen Barnard, Save Your Skin Foundation
Louise Binder Canadian Cancer Survivor Network
Heather Chappell, Kidney Cancer Canada
Annette Cyr, Melanoma Network of Canada
Martine Elias, Myeloma Canada
Elizabeth Lye, Lymphoma Canada
Christina Sit, Lung Cancer Canada
Barry D. Stein, Colorectal Cancer Association of Canada

Sabrina Hanna, Managing Director, Immuno-Oncology Network for Patient Organizations (IONPO)
Natalie Richardson, Project Coordinator, Immuno-Oncology Network for Patient Organizations (IONPO)

Purpose

The purpose of the Patient Leader Education Summit was to ensure that patient advocates working in oncology across Canada had not just a good understanding of the current treatment landscape but also what is in development including the role of companion diagnostics. This includes the system in which decisions for access for these therapies are being made and their role in ensuring access for the patients they represent. It offered a forum to exchange with other patient advocacy groups the work that they were doing and where there could be opportunities for collaboration. Lastly, it was an opportunity to create a unified and cohesive patient advocacy voice for better dialogue and collaboration with the different government agencies and bodies responsible for providing access to cancer therapies and building a better cancer care ecosystem.

Participants



DAY ONE PATIENT LEADER EDUCATION SUMMIT

FRIDAY MARCH 31, 2017

BREAKFAST 8.25-8.55

WELCOME 8.55-9.05

Kathy Barnard, President & Founder
Save Your Skin Foundation

LANDSCAPE OF CANCER TODAY AND TOMORROW

Presentation and Q&A 9.05-10.20

Dr. Marcus Butler, Medical Oncologist
Princess Margaret Cancer Centre

Dr. John C. Bell, Senior Scientist, Centre for Innovative Cancer Research, Ottawa Hospital Research Institute

Monette Greenway, Principal & CO-Founder
Precision Rx Dx

*Moderated by Elizabeth Lye, Scientific Advisor
Lymphoma Canada*

BREAK 10.20-10.30

BUILDING AN IDEAL WORLD FOR IMPROVING PATIENT OUTCOMES IN ONCOLOGY

Panel Discussion and Q&A 10.30-12.00

Dr. Reiner Banken, Senior Fellow
Institute for Clinical and Economic Review (ICER)

Joanne Castonguay, Research Director
Institute for Research on Public Policy (IRPP)

Dr. Femida Gwady-Sridhar, Founder & CEO
Pulse InfoFrame

Martine Elias, Director Access, Advocacy & Community Relations
Myeloma Canada

Moderated by Louise Binder, Health Policy Consultant

LUNCH 12.00-13.00

CURRENT STATE OF AFFAIRS

Panel Discussion and Q&A 13.00-14.30

Marie Hotte, Scientific Coordinator, Drug Evaluation Directorate for Enrolment, Institut national d'excellence en santé et en services sociaux (INESSS) via video

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

Alexandra Chambers, Director
pan-Canadian Oncology Drug review (pCODR)

Heather Logan, Executive Director
Canadian Association of Provincial Cancer Agencies (CAPCA)

Scott Gavura, Director, Provincial Drug Reimbursement Cancer Care Ontario (CCO)

*Moderated by Christina Sit, Program Manager
Lung Cancer Canada*

BREAK 14.30-14.45

CHARTING A COURSE: HOW HIV PAVED THE WAY FOR ADVOCACY IN CANCER

Keynote 14.45-15.00

Ryan Peck, Executive Director
HIV & AIDS Legal Clinic Ontario (HALCO)

OPEN FORUM

Highlight of learnings of the day and key takeaways
15.00-16.30

*Moderated by Martine Elias, Director Access, Advocacy & Community Relations
Myeloma Canada*

COCKTAIL RECEPTION

Official Launch 16.30-18.30

La Maquette
111 King Street

IMMUNO-ONCOLOGY NETWORK FOR PATIENT ORGANIZATIONS

DAY TWO PATIENT LEADER EDUCATION SUMMIT

SATURDAY APRIL 1, 2017

BREAKFAST 8.00-8.30

OPEN FORUM

Environmental Scan 8.30-10.00

A discussion on the current oncology advocacy landscape in Canada to understand what is being done and where the gaps exist.

*Moderated by Sabrina Hanna, Executive Director
Save Your Skin Foundation*

BREAK 10.00-10.15

OPEN FORUM

Roadmapping the Network and Next Steps 10.15-11.50

A discussion on priority setting and tangible areas of improvement in the cancer care delivery and organization eco-system for patient advocates

*Moderated by Sabrina Hanna, Executive Director
Save Your Skin Foundation*

CLOSE

Closing Remarks 11.50-12.00

Barry D. Stein, President
Colorectal Cancer Association of Canada

share the conversation online
#CANCERCARECANADA

An environmental scan opened the second day of the Patient Leader Education Summit to better understand the work that patient advocates were focused on and the gaps that could be filled by the Network.

Identified needs and gaps

- Enhanced collaboration amongst patient advocates
- Tools and resources to assist in the health technology assessment process, including patient submissions
- Better understanding of the treatment landscape, including educational resources, meetings, webinars, and a digital hub
- The Network will represent the patient voice on high level systemic access, health policy and cancer care issues and opportunities
- Support patient advocates in their health policy initiatives
- Opportunity to open up dialogue with all the stakeholders including industry

Deliverables

As a group, we decided that there was a need to work collaboratively in this space and join forces to bring about positive change in cancer care delivery and organization in Canada. It is strongly believed that the patient voice in particular could be engaged to put pressure to make change in cancer care. Collaboration with all stakeholders could produce results in encouraging the approval of cancer treatments and ensuring that patients have equal and timely access to these treatments.

- ❖ A commitment from national and provincial governments to revitalize their cancer strategies.
- ❖ Developing, providing and consolidating the necessary educational tools and resources that would allow patient advocates to make a broader impact for the patients they represent.
- ❖ Open dialogue with the different stakeholders on identifying solutions that improve patient outcomes in oncology in Canada.
- ❖ Delivery of a digital hub with educational resources, materials and tools.
- ❖ Development of a Government Relations strategy including pan Canadian election strategies.
- ❖ Educating the larger public on the status on the research and treatments in precision medicine through a pan-Canadian initiative.
- ❖ Providing the resources necessary for patient advocates to provide patient submissions through the HTA process in partnership with CADTH.
- ❖ Enhancing strategic partnerships with the scientific and medical communities and governments to achieve common objectives.