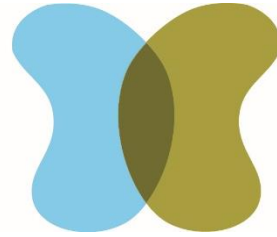


Cancer  
du rein  
CANADA



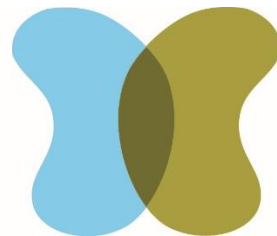
Kidney  
Cancer  
CANADA



**A National Community of Patients,  
Caregivers, and Health Professionals**

**We're Here to Help**

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

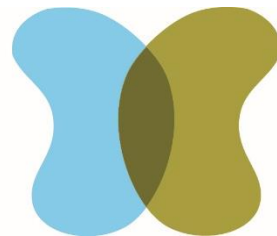
# 2019 Update

Kidney Cancer Forum – April 11, 2019

---

## Introduction

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

## Kidney Cancer in Canada

# 6,600

Canadians diagnosed with kidney cancer\*

\*Source: Canadian Cancer Statistics 2018 – Produced by Canadian Cancer Society, Statistics Canada, Public Health Agency of Canada, Provincial/Territorial Cancer Registries.

# By the numbers

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

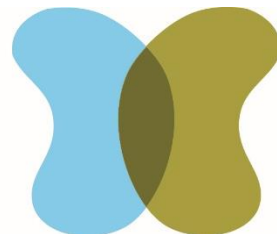
## Kidney Cancer in Canada

# 1,900

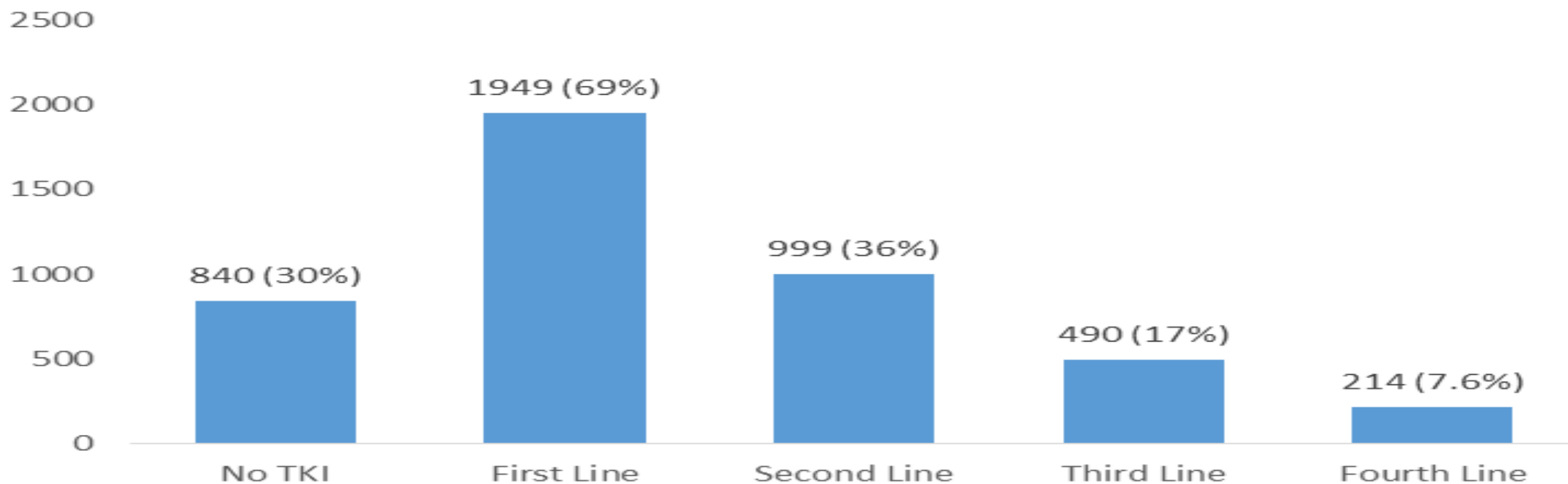
Canadians die from kidney cancer\*

\*Source: Canadian Cancer Statistics 2018 – Produced by Canadian Cancer Society, Statistics Canada, Public Health Agency of Canada, Provincial/Territorial Cancer Registries.

# By the numbers

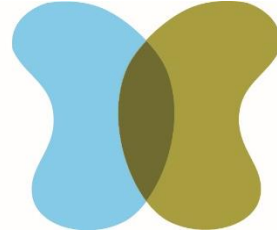


### Treatment for mRCC



**CKCis: 2011 to 2018**

Cancer  
du rein  
CANADA

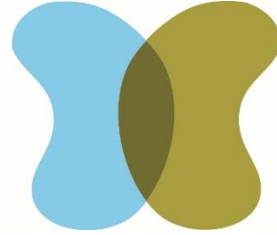


Kidney  
Cancer  
CANADA

To improve the lives of Canadians  
affected by kidney cancer

**Vision**

Cancer  
du rein  
CANADA

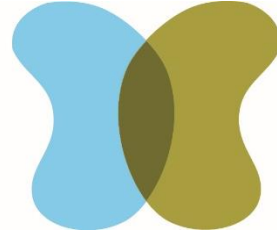


Kidney  
Cancer  
CANADA

- Began in 2017
- Presentation at IKCC - Warsaw
- Patient & Caregiver survey
- July & August

# History of Library

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

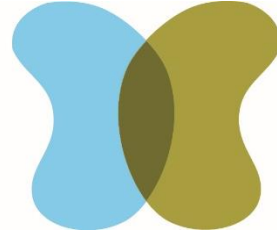
# Patient met or unmet needs

---

**Shared Decision Making**



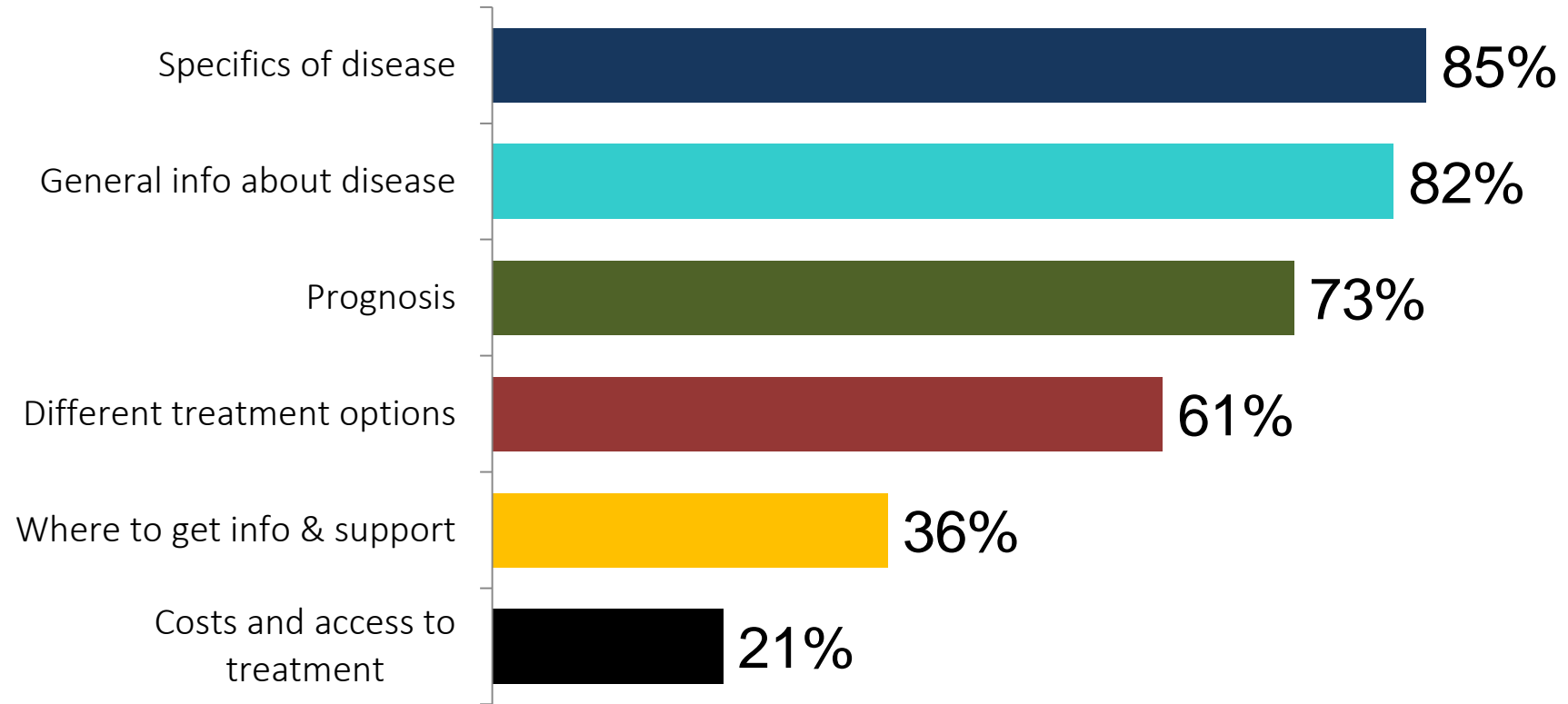
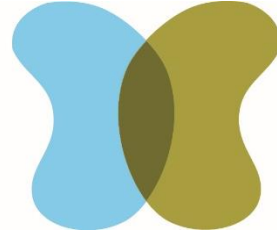
Cancer  
du rein  
CANADA



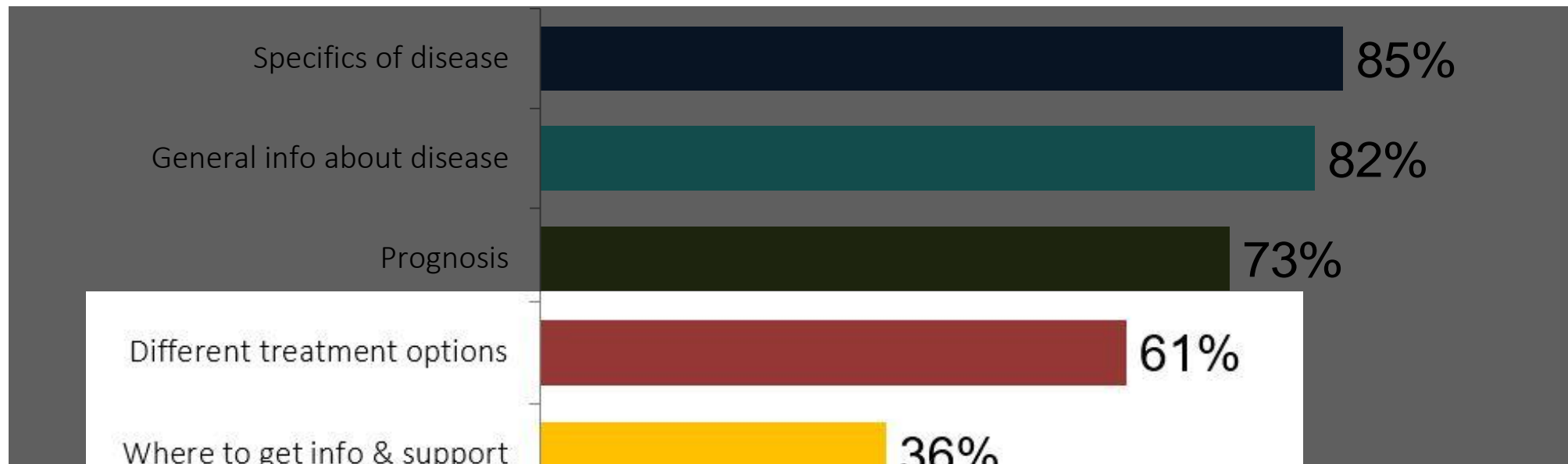
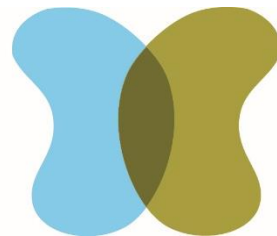
Kidney  
Cancer  
CANADA

When your doctor diagnosed you with kidney cancer, please indicate whether they discussed any of the following with you. Please select all that apply.

**History of Library**



# History of Library



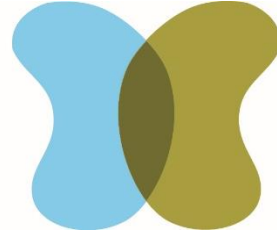
# History of Library



Top 10 supportive care needs	% of individuals who list this as a supportive care need (met or unmet)
To feel like I am managing my health together with my medical team	68%
The very best medical care	66%
To know that all my doctors talk to each other to coordinate my care	66%
Concerns regarding my care to be properly addressed	66%
Local health care services	57%
Information provided in a way that I understand	53%
Help to reduce stress in my life	53%
Help to manage my concerns about the cancer coming back	53%
Up to date information	51%
Emotional support	49%

# History of Library

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

# Common Source Information

---

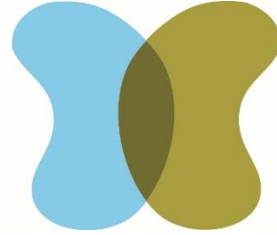
## History of Library



Sources of Info	% Most Common Sources	% Very helpful
Oncologist/Urologist	67%	52%
Kidney Cancer Canada	55%	35%
Family doctor	50%	25%
Nurses	10%	8%
Online social groups	9%	2%

# History of Library

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

Oncologist/Urologist	67%	52%
Kidney Cancer Canada	55%	35%
Family doctor	50%	25%



# History of Library

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA



Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

# Kidney Cancer Video Knowledge Library

IKCC – April 3, 2019

# History of Library



Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA



Search



PATIENTS &  
CAREGIVERS

MEDICAL  
PROFESSIONALS

NEWS +  
EVENTS

ABOUT US

SUPPORT US

CONTACT



Hootlet

Cancer du rein CANADA  Kidney Cancer CANADA

# Kidney Cancer Video Knowledge Library

an exciting new resource for patients,  
caregivers, and healthcare professionals!



 NEWLY  
DIAGNOSED

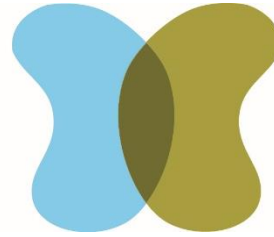
 CALENDAR  
OF EVENTS

 DISCUSSION  
FORUM

 VIDEO  
KNOWLEDGE  
LIBRARY

[kidneycancercanda.ca](http://kidneycancercanda.ca)

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA



**Kidney Cancer  
Video Knowledge Library**

The Kidney Cancer Video Knowledge Library answers questions from patients and caregivers by leading kidney cancer specialists across Canada.

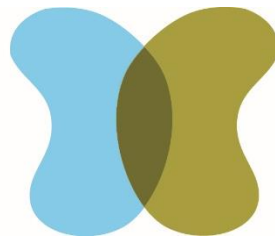
The information provided in Kidney Cancer Video Knowledge Library is purely informative and is not a definitive diagnosis. For any health concerns see your doctor.

*La version en français de la Vidéothèque du savoir est prévue au printemps 2019*

Symptoms of kidney cancer	How do we diagnose kidney cancer?	Post kidney cancer diagnosis
Before kidney cancer surgery	Kidney cancer surgery	Post kidney cancer surgery
Localized kidney cancer	Advanced kidney cancer	Have a question? Submit it here.

**kidneycancercanda.ca**

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

Symptoms of  
kidney cancer

How do we  
diagnose  
kidney cancer?

Post kidney  
cancer diagnosis

Before kidney  
cancer surgery

Kidney cancer  
surgery

Post kidney  
cancer surgery

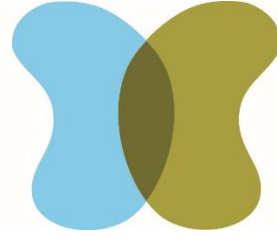
Localized  
kidney cancer

Advanced  
kidney cancer

Have a question?  
Submit it here.

[kidneycancercanda.ca](http://kidneycancercanda.ca)

Cancer  
du rein  
CANADA

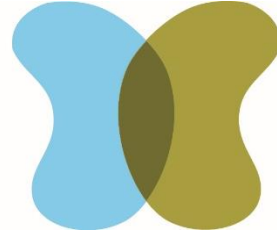


Kidney  
Cancer  
CANADA

# Live Demonstration

[kidneycancercanda.ca](http://kidneycancercanda.ca)

Cancer  
du rein  
CANADA

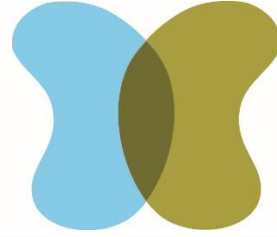


Kidney  
Cancer  
CANADA

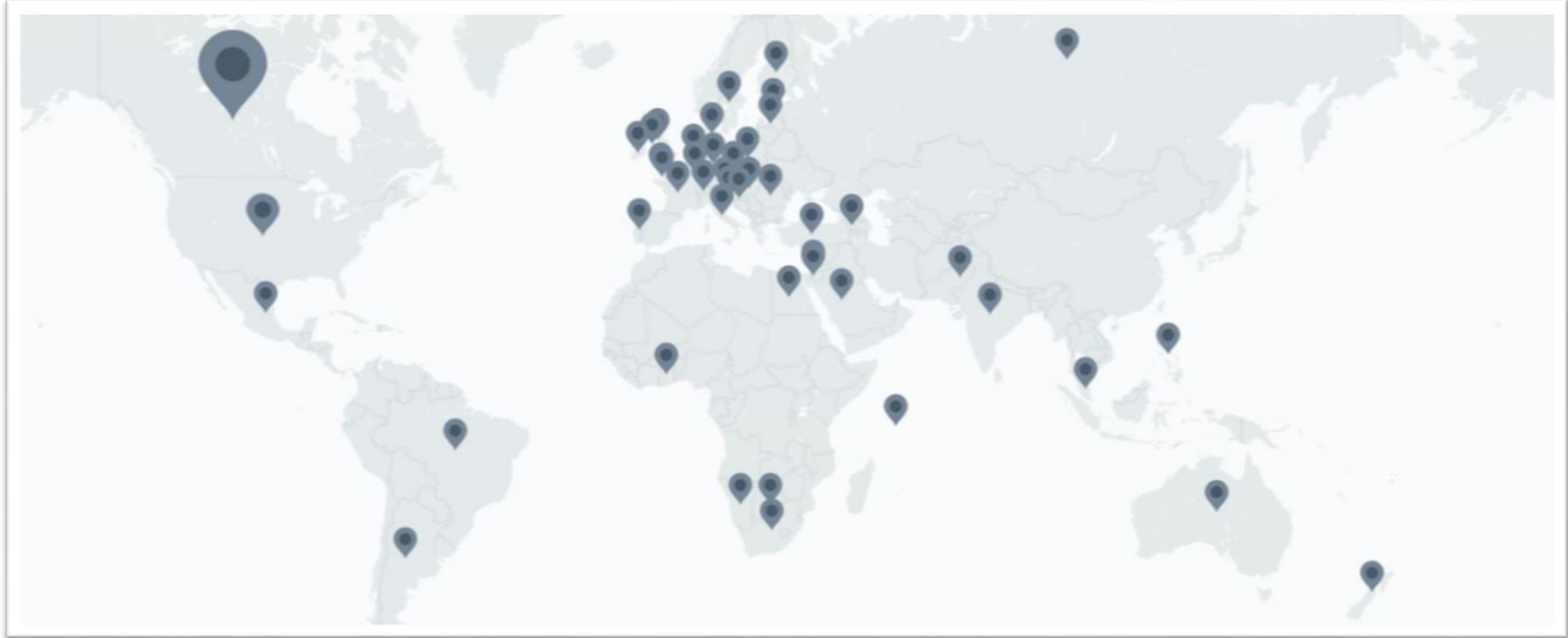
# The Results

[kidneycancercanda.ca](http://kidneycancercanda.ca)

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA



# Global Visits

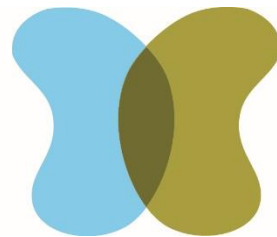
Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

+ Canada	+ New Zealand	+ India
+ United States	+ Malaysia	+ Mexico
+ Australia	+ Ireland	+ Italy
+ United Kingdom	+ Romania	+ France
+ Germany	+ Pakistan	

**Top Country Usage**

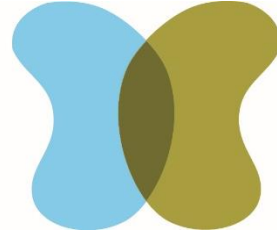


1	What are symptoms of kidney cancer?
2	How has survival changed over the past five years?
3	Typically, how fast do kidney tumours grow?
4	How important is it to know my histology?
5	Does having my tumour removed mean I am cured?
6	What can I expect when waking up from a nephrectomy?
7	What is 'Stage 4' kidney cancer?
8	What is a radical nephrectomy?
9	What is 'Stage 1' kidney cancer?
10	What is a TKI?

# Top Ten Views



Cancer  
du rein  
CANADA

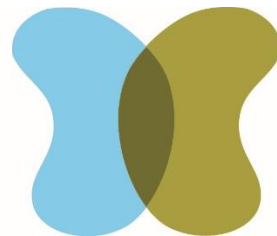


Kidney  
Cancer  
CANADA

# Other Projects

[kidneycancercanda.ca](http://kidneycancercanda.ca)

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

**2019**  
**VAN**  
**COU**  
**VER**

Cancer du rein CANADA  Kidney Cancer CANADA

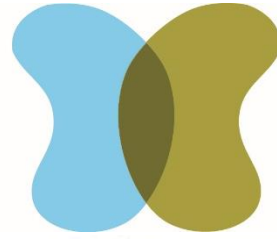
**Annual Patient +  
Caregiver Forum**

Saturday, April 27  
8:30 AM - 4:30 PM  
Sandman Hotel  
180 West Georgia St  
Vancouver, BC



**kidneycancercanda.ca**

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

# KIDNEY CANCER

*We need to talk*

World Kidney Cancer Day 20 June 2019



**World Kidney Cancer Day**



CANADIAN KIDNEY CANCER information system

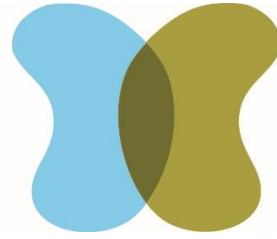
**Resolving Uncertainty with**

**Real World**

**Evidence**



Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

Jessica  
Arias  
CCO

Kim  
Castelano  
CADTH

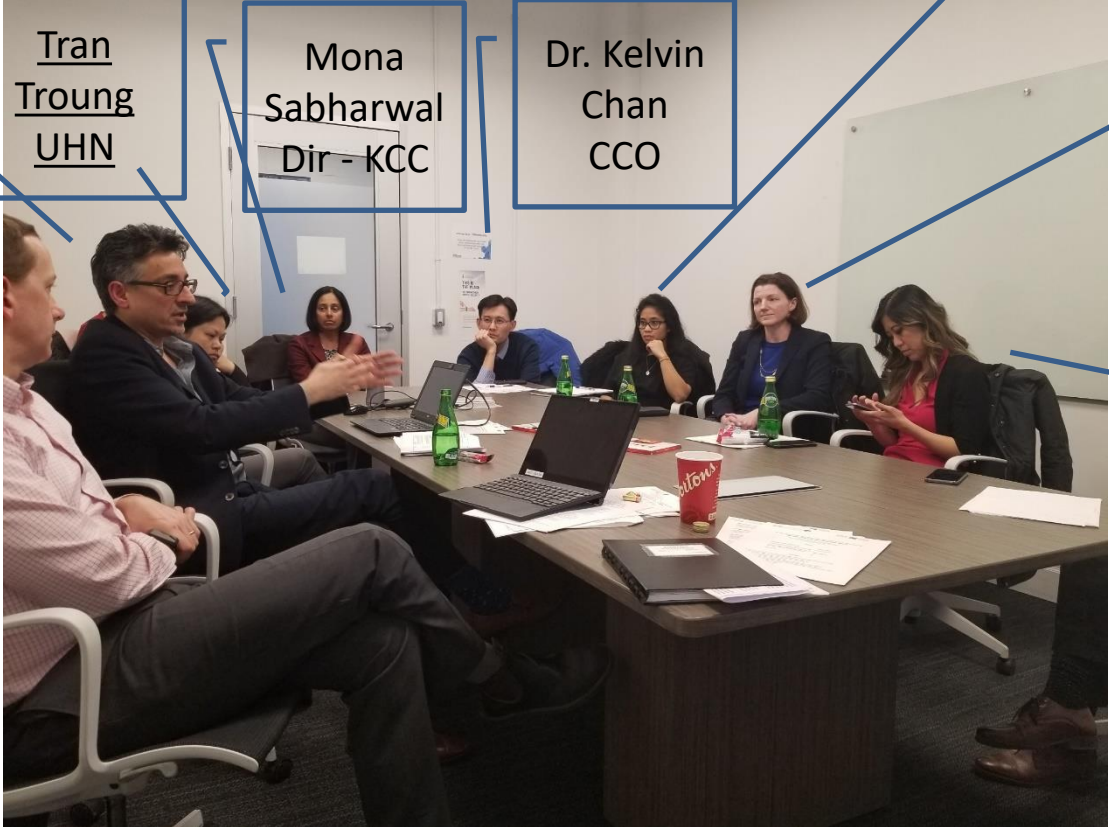
Scott Gavura  
CCO

Tran  
Truong  
UHN

Mona  
Sabharwal  
Dir - KCC

Dr. Kelvin  
Chan  
CCO

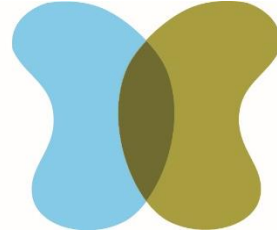
Alex  
Chambers  
pCODR



Sang Mi Lee  
pCPA

# Advocacy

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

**McDreamy**



[kidneycancercanda.ca](http://kidneycancercanda.ca)



## **pCODR - Request for Advice: CKCis Real World Evidence (RWE)**

- April 2017, Provincial Advisory Group (PAG) submitted a RFA to pCODR regarding the (March 2013) Final Recommendation (re axitinib):

***Is there evidence to fund axitinib as an alternative to everolimus for the second-line treatment of metastatic clear cell renal carcinoma?***

- CKCis investigators made the RFA question a research priority

Cancer  
du rein  
CANADA



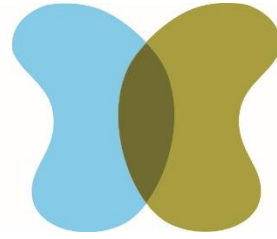
Kidney  
Cancer  
CANADA

- Patient Orientation Sessions
- Regional Meetings
- Expand professional outreach
- Conferences meetings

**Moving forward**



Cancer  
du rein  
CANADA



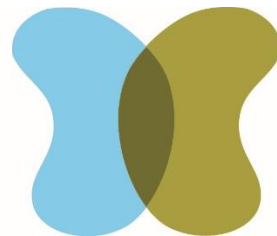
Kidney  
Cancer  
CANADA

- Patient Care Kits
- Move to Beat Cancer - September
- Patient Sovereignty
- Working with clinician and patient groups

---

**Moving forward**

Cancer  
du rein  
CANADA



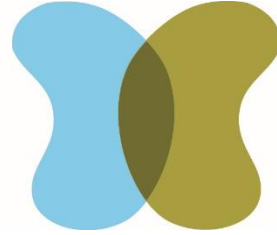
Kidney  
Cancer  
CANADA

- Formed in 2007
- Move to Beat Cancer - September
- Patient Sovereignty
- Working with clinician and patient groups

---

# History

Cancer  
du rein  
CANADA



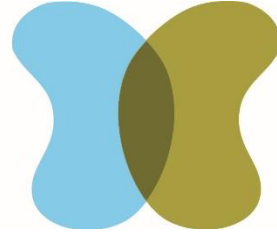
Kidney  
Cancer  
CANADA

# Patient Sovereignty

---

**What we see**

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA



*"When we want your opinion,  
we'll give it to you."*

# Shared Decision Making

Cancer  
du rein  
CANADA

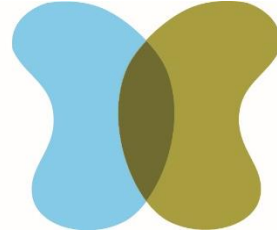


Kidney  
Cancer  
CANADA

How can we empower patients  
in this decision-making process?

**Shared Decision Making**

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

# Engagement

**By the numbers**

2017

680,000

Online impressions

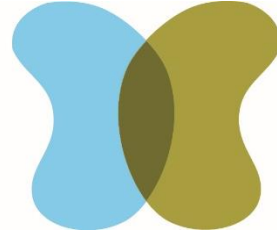
2018

1,000,000

Online impressions



Cancer  
du rein  
CANADA

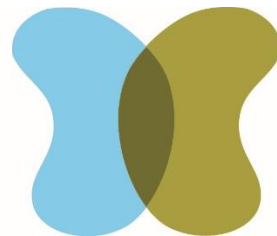


Kidney  
Cancer  
CANADA

# The Future

2019

Cancer  
du rein  
CANADA

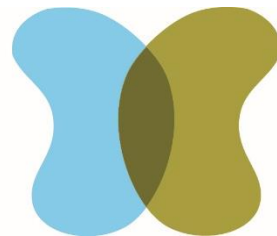


Kidney  
Cancer  
CANADA

RWE can and should be used to resolve uncertainty. In Canada, the opportunity to generate high quality evidence prospectively is available through the Canadian Kidney Cancer information system (CKCis)

**Shared decision making**

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA

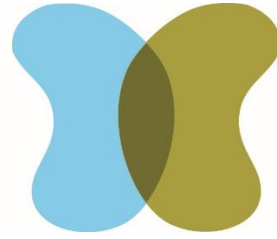


Formed more than 12 years  
ago by cofounders

Tony Clark & Deb Maskens

# History

Cancer  
du rein  
CANADA



Kidney  
Cancer  
CANADA



**Thank you**