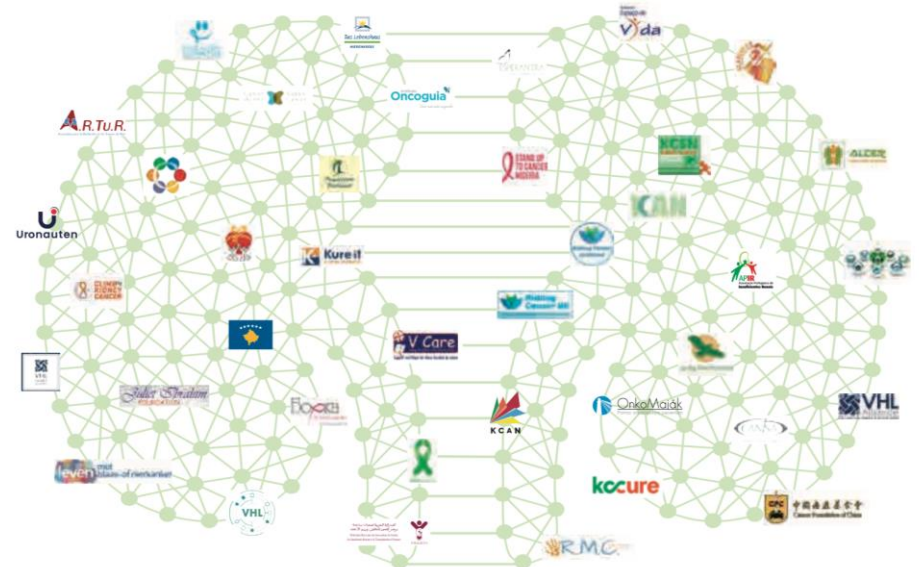


IKCC Current Initiatives and Future Plans

International Kidney Cancer Coalition
Amsterdam, The Netherlands
Stichting IKCC Foundation
www.ikcc.org

Deb Maskens, IKCC Vice Chair
@DebMaskens
@IKCCorg



AGENDA

(1) What is the IKCC?

(2) IKCC Involvement, Projects, Progress 2019

(3) Addressing Unmet Needs for RCC Patients Worldwide
Medical Needs / Health System & Health Policy Needs

(4) Future Directions for IKCC

The IKCC Network 2019

Reaching over 1.2 million kidney cancer patients worldwide



Please check our website for the latest list of organisations who have joined IKCC.

Affiliate Organisations can be identified by this logo displayed on their website and materials.



39 Affiliates

25 Countries

6 Continents



The IKCC: Our Leadership Team



Board of Directors

- Patients, Caregivers, Medical Professionals
- 6 Countries (AU, CDN, DE, NL, UK, USA)



Operations Manager

Julia Black



Medical Advisory Board

Executive:

- Dr Michael Jewett (Chair)
- Dr Eric Jonasch (Vice Chair)
- Prof. Axel Bex (NL/UK)
- Dr Daniel Heng (CDN)
- Prof. James Larkin (UK)



Members Worldwide:

- Australia, Brazil, India, Poland, Singapore, Mexico, China, Japan, UK

Global Summit & Experts Meeting April 4-6 2019



53 Patient Advocates
26 Countries
6 Continents



Global Summit & Experts Meeting 2019

Keynote Address



Dr. Serena Barello



Catholic University of the Sacred Heart
Milan, Italy, Italy

RESEARCH ARTICLE

The role of Patient Health Engagement Model (PHE-model) in affecting patient activation and medication adherence: A structural equation model

Guendalina Graffigna^{1*}, Serena Barello¹, Andrea Bonanomi²

¹ Department of Psychology, Università Cattolica del Sacro Cuore, Milan, Italy, ² Department of Statistical Sciences, Università Cattolica del Sacro Cuore, Milan, Italy

* guendalina.graffigna@unicatt.it



New Groups



Advocacy in Portugal

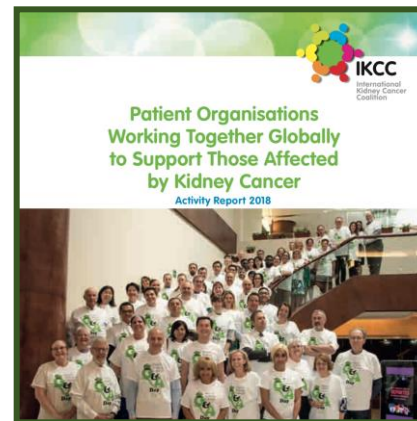


Focus on Global Collaboration



Each year:

- Kidney Cancer Global Summit
- IKCC Global Board & Working-Meetings
- Communications
- Close Collaboration with KOLs and other Stakeholders
- Task Forces & Roundtables
- Publications
- Activity/Conference Report



Sustaining Partners 2019

BMS Eisai Exelixis
MerckMSD Novartis Pfizer

MerckKGaA*
** Partial funding*

To Reduce Global Burden of Kidney Cancer



GLOBAL OUTREACH



World Cancer Congress
Kuala Lumpur, Malaysia
1-4 Oct 2018

Strengthen
Inspire
Deliver



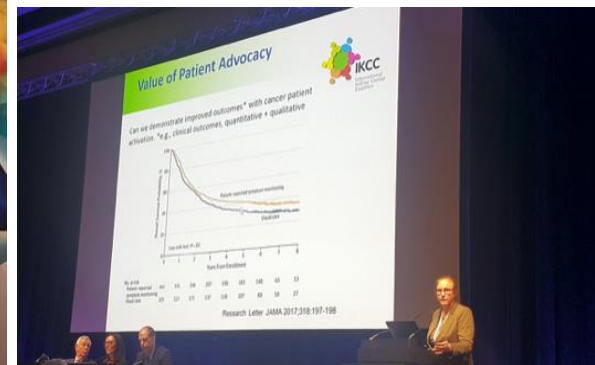
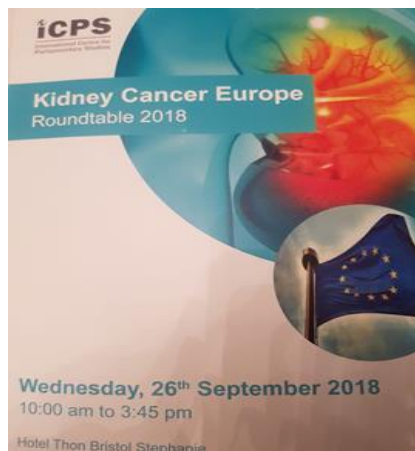
2019 ASCO
ANNUAL MEETING
May 31 - June 4, 2019
McCormick Place | Chicago, IL
#ASCO19

Regional Outreach

Advocacy Initiatives

Publications, Partnerships

- **CHMP/EMA Committee**
- **EAU PAG Working Group (EPAWG)**
- **EAU Guidelines**
- **NCI Renal Task Force**
- **NCCN Guidelines**
- **European Policy Forum**
- **Support to World Bladder Cancer Coalition**



2018 IKCC Publications



- **Patient value: Perspectives from the advocacy community.**
Health Expect. 2018 Feb;21(1):57-63.
- **Updated European Association of Urology Guidelines for Cytoreductive Nephrectomy in Patients with Synchronous Metastatic Clear-cell Renal Cell Carcinoma.**
European Urology 2018 Dec;74(6):805-809.
- **Adjuvant vascular endothelial growth factor (VEGF) targeted therapy in renal cell carcinoma: a systematic review and pooled-analysis.**
European Urology. 2018 Nov;74(5):611-620.
- **An interdisciplinary consensus on the management of bone metastases from renal cell carcinoma.**
Nature Reviews Urology 2018; 15(8), pages 511–521.
- **Imaging in Suspected Renal Cell Carcinoma: A Systematic Review**
Clinical Genitourinary Cancer 2018; Aug 11, doi: 10.1016/j.clgc.2018.07.024.
- **A Joint Statement from the European Association of Urology Renal Cell Cancer Guidelines Panel and the International Kidney Cancer Coalition: The Rejection of Ipilimumab and Nivolumab for Renal Cancer by the Committee for Medicinal Products for Human Use Does not Change Evidence-based Guideline Recommendations.**
European Urology 2018 Dec;74(6):849-851.

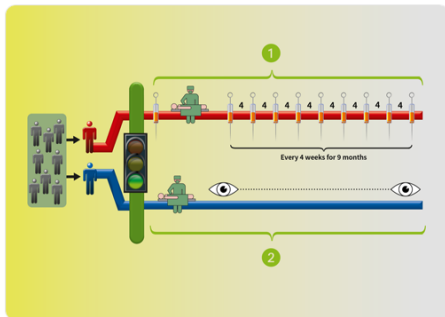
Social Media: Think Treatment? Think Trials!



IKCC Kidney Cancer Retweeted

IKCCtrials @IKCCtrials · Mar 4

On our radar of important [#clinicaltrials](#) in [#kidneycancer](#) for 2019: PROSPER RCC for patients PRE and POST nephrectomy bit.ly/IKCC-PROSPER @IKCCOrg



IKCC Kidney Cancer @IKCCOrg · Feb 26

Important new [#clinicaltrial](#) opportunity seeks to determine best sequential therapy following 1st line [#immunotherapy](#) combo @IKCCtrials [#KidneyCancer](#) clinicaltrials.gov/ct2/show/NCT03...



Tian Zhang @TiansterZhang

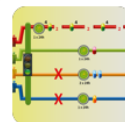
Our phase 3 @ALLIANCE_org PDIGREE trial aims to improve on current standard with ipi-nivo, with induction combination IO, followed by randomization to nivolumab vs nivolumab based on response. Primary endpoint OS,...

Show this thread



IKCC Kidney Cancer @IKCCOrg · Feb 27

Patients with [#papillary](#) [#kidneycancer](#) in U.S. and Canada can ASK about this clinical trial opportunity. Recruiting into remaining two arms, cabozantinib or sunitinib. If papillary, think trials...



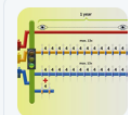
IKCCtrials @IKCCtrials

Important NCI-sponsored [#clinicaltrial](#) for [#papillary](#) [#kidneycancer](#) patients nearing completion of accrual with two remaining arms: sunitinib vs. cabozantinib (S1500) bit.ly/S1500-IKCC @IKCCOrg



IKCC Kidney Cancer @IKCCOrg · Mar 12

This is a BIG trial. Will recruit 1750 [#kidneycancer](#) patients post-nephrectomy. Open in sites across UK now with more countries to come. [#adjuvant](#) [#immunotherapy](#) [#noplacebo](#) [#clinicaltrials](#)



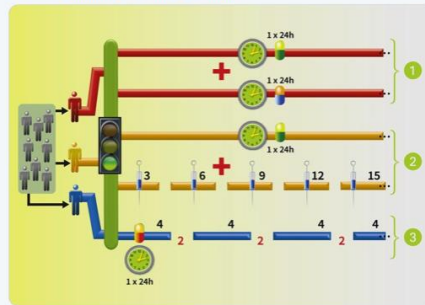
IKCCtrials @IKCCtrials

Good to see RAMPART Adjuvant RCC trial up and running in UK. Patients are asking about it! Two active arms vs. close observation post nephrectomy: bit.ly/IKCC-RAMPART @IKCCOrg [#kidneycancer](#)



IKCCtrials @IKCCtrials · Mar 18

Ongoing Phase 3 CLEAR clinical trial for [#kidneycancer](#) patients in Australia, Austria, Belgium, Canada, Czechia, France, Germany, Greece, Ireland, Israel, Italy, Japan, South Korea, Netherlands, Poland, Russia, Spain, Switzerland, UK and USA. bit.ly/IKCC-Lenvatinib @IKCCOrg



IKCCtrials @IKCCtrials · 18h

New: Check out our infographic of the KEYNOTE-426 [#clinicaltrial](#) results in visual form: bit.ly/IKCC-Infograph... [#kidneycancer](#) [#immunotherapy](#) [#pembrolizumab](#) [#axitinib](#) [#sunitinib](#) @IKCCOrg

Study Results Keynote-426

A study of pembrolizumab plus axitinib versus sunitinib as first-line therapy for locally advanced or metastatic renal cell carcinoma

source : ASCO GU 2019, <https://meetinglibrary.asco.org/record/170343/abstract>



861
Patients



129
Trial Sites



16
Countries

Digital Tools: New E-Atlas and Info Hub



Kidney Cancer in France

Overview Clinical Trials Patient Organisations Glossary

Kidney Cancer in France

World Health Organisation Cancer Country Profile for France

Incidence

Age-standardised rate of kidney cancer cases (per 100,000 persons per year) (2018)

Men:	17.5
Women:	7.9
Men & Women:	12

Mortality

Age-standardised kidney cancer death rate (per 100,000 persons per year) (2018)

Men:	4.5
Women:	1.8
Men & Women:	3.1

Prevalence

Estimated number of prevalent kidney cancer cases (proportion per 100,000) per year (2018)

Estimated Prevalence (5 year):	66
--------------------------------	----

Prevalence is defined as the number or percent of people alive on a certain date in a population who previously had a diagnosis of the disease. It includes new (incidence) and pre-existing cases and is a function of both past incidence and survival.

Global Data

Kidney Cancer Incidence Worldwide

Men: [download pdf](#) Women: [download pdf](#) Men & Women: [download pdf](#)

Kidney Cancer Mortality Worldwide

Men: [download pdf](#) Women: [download pdf](#) Men & Women: [download pdf](#)

Kidney Cancer Prevalence (5-year) Worldwide


Men: [download pdf](#) Women: [download pdf](#) Men & Women: [download pdf](#)

Kidney Cancer in France

Overview Clinical Trials Patient Organisations Glossary

IKCC Affiliate Organisations

Association pour la Recherche sur les Tumeurs du Rein

 A.R.Tu.R. (Association pour la Recherche sur les Tumeurs du Rein) est une association loi 1901, créée en 2005, qui a la particularité de regrouper à la fois des médecins, des patients et des proches de malades. Ses objectifs sont, d'une part, soutenir et développer la recherche sur les tumeurs du rein et leur prise en charge clinique (volet médical), et d'autre part, améliorer l'information des patients, de leur famille, et les aider à vivre avec un cancer du rein (volet patients). Association pour la Recherche sur les Tumeurs du Rein

Other Organisations

We are not aware of any other organisations serving kidney cancer patients in this country. Please refer to our global network to identify affiliated organisations closest to you: [our global network](#).

If you are aware of an organisation that serves kidney cancer patients in this country, please send the organisation's details to: info@ikcc.org



Graphics, Infographics and Images



Factsheet: Types of kidney cancer



Clinical Trials



Clinical Trials Database & Search Engine



<https://ikcc.org/clinical-trials-search/>

Last updated: March 25, 2019

Search
Reports
Results

Country

- ▶ all countries (with available trials)
- Austria
- Belarus
- Belgium
- Bosnia and Herzegovina
- Brazil
- Bulgaria
- Cameroon
- Canada
- Chile
- China

Powered by: **clinical trials**
March 25 2019

Suchfeld	Wert
Country	Brazil
Status of trials	recruiting

Trial name or number	Study type	Keyword (e.g. name of drug, treatment)	Phase of Trial	Status	Country
A Study Comparing the Combination of Nivolumab and Ipilimumab Versus Placebo in Participants With Localized Renal Cell Carcinoma (CheckMate 914)	Interventional	Biological: Nivolumab (Specified dose on specified days for 24 weeks) Biological: Ipilimumab (Specified dose on specified days for 24 weeks) Drug: Placebo (Specified dose on specified days for 24 weeks)	phase 3	Recruiting	Argentina; Australia; Austria; Belgium; Brazil; Canada; China; Czech Republic; France; Germany; Italy; Japan; Mexico; Netherlands; Poland; Russian Federation; Singapore; Spain; United Kingdom; United States
A Study of Atezolizumab as Adjuvant Therapy in Participants With Renal	Interventional	Drug: Atezolizumab (Atezolizumab 1200 mg IV infusion q3w) Other: Placebo (Placebo matching to atezolizumab q3w)	phase 3	Recruiting	Argentina; Australia; Austria; Belgium; Brazil; Canada; Chile; China; Czech Republic; Denmark; France; Germany; Ireland; Israel;

Type of kidney ▶ all kidney cancer subtypes

(Brazil: 7 studies ongoing)

Study Results Checkmate 214

nivolumab combined with ipilimumab versus cetuximab

in previously untreated advanced or metastatic renal cell carcinoma

Source: Sznol et al. *Journal of Clinical Oncology* 35:1935-1944 (2017). doi:10.1200/JCO.2016.35.1935. Received November 10, 2016; accepted February 1, 2017. Published online first on www.jco.org on February 1, 2017.



1070 Patients

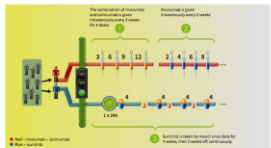


184 Trial Sites

Trial Design



27 Countries



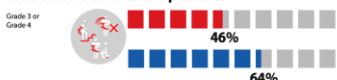
Patients with favourable risk¹



Patients with intermediate/poor risk²



Side effects all treated patients



Study Results Javelin Renal 101

A study of avelumab with axitinib versus sunitinib

in advanced renal cell cancer

Source: www.escmp.org/Press-Office/Press-Release/Javelin-101-renal-cancer-immunotherapy-Molitor

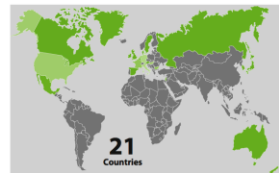


886 Patients

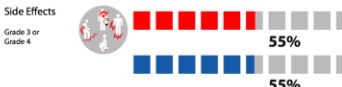
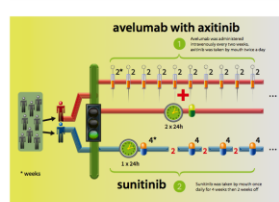


273 Trial Sites

Trial Design



21 Countries



Study Results Keynote-426

A study of pembrolizumab plus axitinib versus sunitinib as first-line therapy for locally advanced or metastatic renal cell carcinoma

Source: ASCO GU 2019, <https://meetinglibrary.asco.org/record/170343/abstract>



861 Patients

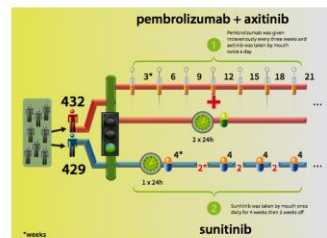


129 Trial Sites

Trial Design



16 Countries



World Kidney Cancer Day 2019 theme

**KIDNEY
CANCER**

We need to talk



We need to talk because most people have never heard of kidney cancer.

We need to talk to encourage more clinical trials, more discussion of the psychological effects, more involvement of patients in treatment decisions, etc.

We need to talk because only by talking will we create the awareness and urgency to bring about better prevention, research, care and patient outcomes.

IKCC Global RCC Patient Survey Findings



- **1,983 Respondents**
- **43 Countries**
- **14 Languages**
- **30 Patient Groups**



Key Areas of Inquiry:

- **Clinical Trials**
- **Patient Information & Shared Decision Making**
- **Quality of Life**

	Respondents	Proportion
Canada	246	12%
France	238	12%
United States	233	12%
South Korea	229	12%
Japan	195	10%
United Kingdom	181	9%
Mexico	144	7%
India	140	7%
Germany	128	6%
Brazil	51	3%
Netherlands	46	2%
Australia	38	2%
Finland	31	2%
Other	34	4%

Global Participation

Total: 1,983 patients/carers

The largest kidney cancer patient experience survey to date



1. Patient Understanding

- 43% of patients had No Understanding of SubType at diagnosis **(42%)**

2. Clinical Trials

- 70% of patients have never been Asked to join a clinical trial **(60%)**
- Of those never asked, 89% would be 'fairly likely to join **(89%)**
- 45% of those patients already being treated at Major Cancer Centres

3. Shared Decision Making

- 29% report "My Doctor Decided For Me" **(25%)**

4. Quality of Life

- 96% of all patient report psychosocial impacts **(92%)**
 - Only 50% of them are discussing with HCPs **(58%)**

Future Directions for IKCC



Informed by Global Patient Survey 2018



- Support Diagnosis: Decision Aids for Localised Kidney Cancer**
- Managing toxicities (short-term and prolonged) of combination therapies: paper based on RWE**
- Management of Oligometastatic mRCC: paper**
- Long-term survivors (5+ years): paper**
- Cross-GU Collaborations: eg. WBCC, UICC, SIU, EAU, ESMO**

Where can IKCC Best Address Unmet Needs at the Global Level?



Awareness of RCC / Advocacy for Best Practices

Raise Awareness

Patient Education, Information

Research

Clinical Trial Design, Patient Reported Outcomes

Communication across the IKCC Network

Regulatory/HTA

Provide patient voice; perspective; new insights

Real World Evidence

Emerging Markets

Support needs of patients, organisations, associations

Thank you for your ongoing support!



Discussion

