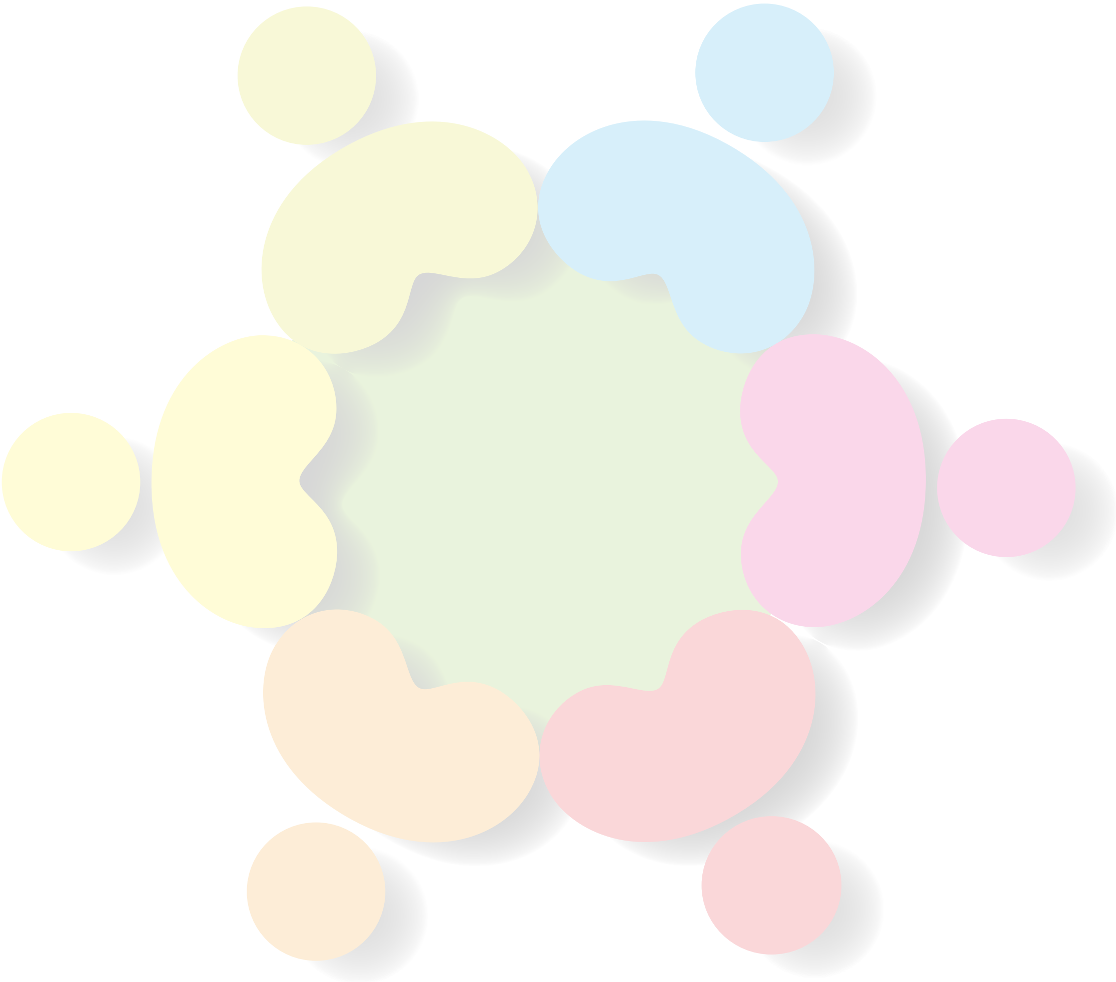
IKCC

International
Kidney Cancer
Coalition

Patient Organisations Working Together Globally to Support Those Affected by Kidney Cancer

Annual Report 2019



Content

Message from the Chair

The International Kidney Cancer Coalition (IKCC) is the only global network of independent national kidney cancer patient organisations. We represent the perspectives, insights and experiences of kidney cancer patients around the world and empower the kidney cancer community through advocacy, awareness, information and research.

Together, we strive towards one shared goal: to reduce the global burden of kidney cancer.

Each year, IKCC has continued to grow and mature as an organisation. This is achieved through the dedicated vision and continuous commitment from Affiliate Organisations, our Medical Advisory Board and Board of Directors. In turn, IKCC's governance has also evolved and we are pleased to present this Annual Report for 2019, which includes a full set of audited financial statements, along with the year's highlights.

In 2019, IKCC's Global Kidney Cancer Summit brought together more members of the kidney cancer community than ever before. Gathered in Lisbon, Portugal, we explored access to care, shared decision making, clinical trials and unmet medical and psycho-social needs of patients and carers. The annual event serves as a hub for education, collaboration and networking that advances our collective goals to improve patient care and support.

An evidence-based organisation, IKCC launched its first Global Patient Survey in 2018 to address the gap in research related to the patient experience worldwide. In 2019, it was time to talk about kidney cancer and we shared global and country-specific results through presentations and posters. Highlights include participation at the European Society of Medical Oncology in Spain, IPOS World Congress of Psycho-Oncology and Psycho-social Academy in Canada and the International Kidney Cancer Symposium in the United States. The second iteration of the survey is in development for 2020.

It is an organizational priority to bring patients' voices and priorities closer to the implementation of best practices for kidney cancer. We continue our work on guidelines committees, health technology assessments, and patient involvement in the design of clinical trials for kidney cancer worldwide. We have co-authored eight papers in medical journals this year alone and attended a 2019 Policy Roundtable in Brussels with members of the European Parliament to discuss funds for promoting awareness and research in kidney cancer.

As we close on 2019 and look ahead to the next decade, we are inspired by the groundswell of support for our vision and the formation of alliances between like-minded organisations and individuals. It is the sum of our parts that make a global impact. For this reason, we continue to welcome and encourage organisations with an interest in kidney cancer to join our international network.

On behalf of the Board of Directors and the dedicated IKCC staff, we thank each and every person who contributed to the tremendous success in 2019. Affiliate Organisations, healthcare professionals, patients and carers and supporting partners have all played a role in our success. Because together we are stronger.

Dr Rachel Giles,

Chair of the Board

About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of patient organisations that focus exclusively, or include a specific focus, on kidney cancer. The organisation was born from a very strong desire among various national kidney cancer patient groups to network, cooperate and share materials, knowledge, and experiences.

Kidney cancer is a global issue. Every year, 403,000 people worldwide will be diagnosed with kidney cancer. Research and clinical trials in kidney cancer take place across continents and many kidney cancer experts sit on international panels. By working together and collecting the experiences of many patients in different countries, we represent the perspectives, insights and experiences of kidney cancer patients around the world and empower the kidney cancer community through advocacy, awareness, information and research.

Our Mission:

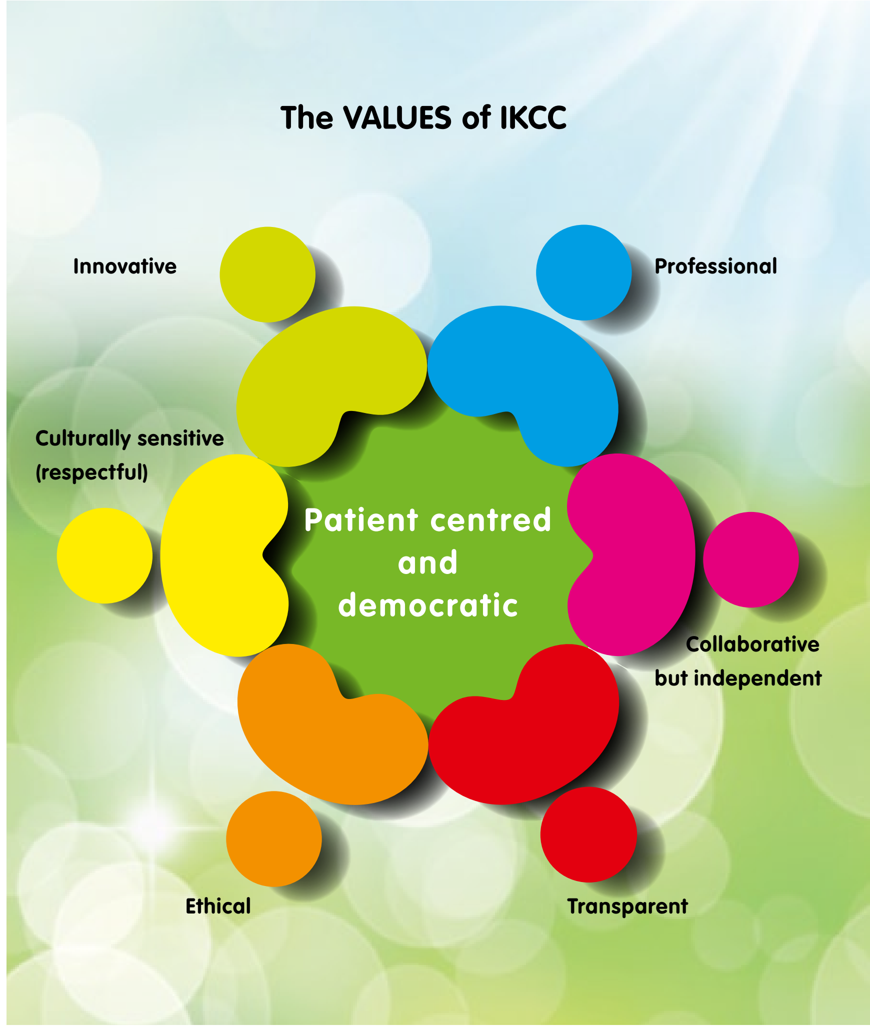
IKCC is a global collaboration of patient organisations that empowers and represents the kidney cancer community through advocacy, awareness, information and research.

Our Vision:

To reduce the global burden of kidney cancer.

Our Values:

Values are an integral part of every culture – they are central to any organisation. IKCC has defined core values that form the basis for the culture, the behaviour, the cooperation, the decision-making process and the activities of IKCC.



2019: IKCC by the Numbers

43
Affiliate Organisations worldwide

6
new Affiliate Organisations on
4
continents joined IKCC

Nearly **4,000**
Twitter followers and over
9,000
likes on Facebook

500,000
social media impressions worldwide

50 patient advocates from
26 countries and
6 continents attended the Global Summit in Portugal

Over **33,000** people visited the World Kidney Cancer Day website and nearly
6,000 people completed the quiz

IKCC co-authored **8** articles in medical journals

Presented Global Patient Survey results at
5 international conferences

7 editions of the IKCC Newsletter sent to
327 subscribers

Projects and Activities 2019

Global Patient Survey – The Kidney Cancer Experience Worldwide

At last year's Global Summit, we presented the top-level results of the 2018 Global Patient Survey, the first-ever international survey of kidney cancer patient and carer experiences. Thank you to all of the patient organisations who collaborated with us to ensure a truly global voice. In all, 1,983 patients and carers from 43 countries completed the survey.

Throughout 2019, we communicated the results broadly to highlight many unmet patient and carer needs – and also to plan for further investigation into key areas in our next global survey in 2020.

Survey results were presented at:

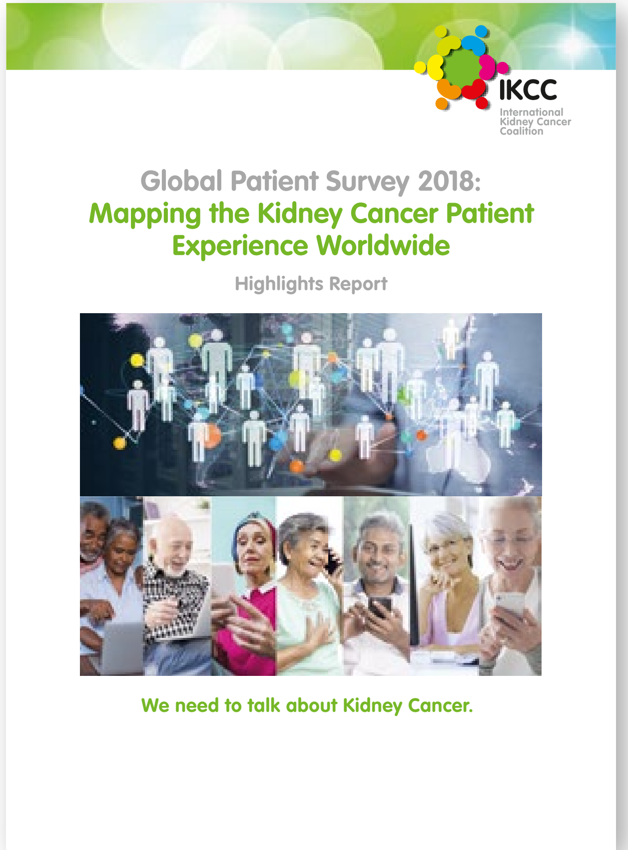
- IKCC Global Summit, Portugal, April 2019
- Canadian Kidney Cancer Research Network Conference, Canada, April 2019
- International Psycho-Oncology Conference (IPOS), Canada, September 2019
- European Society of Medical Oncology (ESMO), Spain, September 2019
- International Kidney Cancer Symposium (IKCS), USA, November 2019

In addition to these presentations, we have joined Affiliate Organisations in seizing every opportunity to communicate the results at national and international kidney cancer meetings. Our independently analyzed survey results offer high-quality evidence that kidney cancer patients need more information about their disease, more input into decision making, and more support for psychological impacts.

Feedback from organisations around the world has indicated the strength of this data for use in medical experts' meetings, at patient education meetings, and as a robust evidence base for submissions to government authorities concerning kidney cancer at the national and international levels.

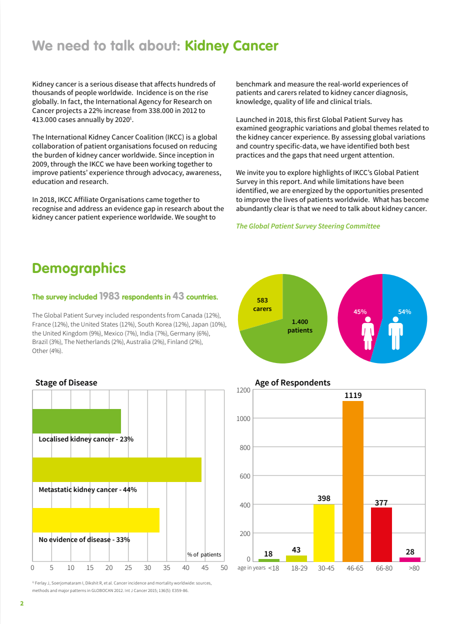
An 8-page summary report and accompanying infographic provide a high-level introduction to a wealth of data. These summaries, along with the Global report and Country reports are available on the IKCC website: ikcc.org/global-patient-survey

We look forward to working with a multi-country steering group of patient organisations to design the 2020 patient survey to track progress, analyse trends, and delve more deeply into areas of inquiry most important to the kidney cancer patient community.


IKCC
International Kidney Cancer Coalition

Global Patient Survey 2018:
Mapping the Kidney Cancer Patient Experience Worldwide
Highlights Report

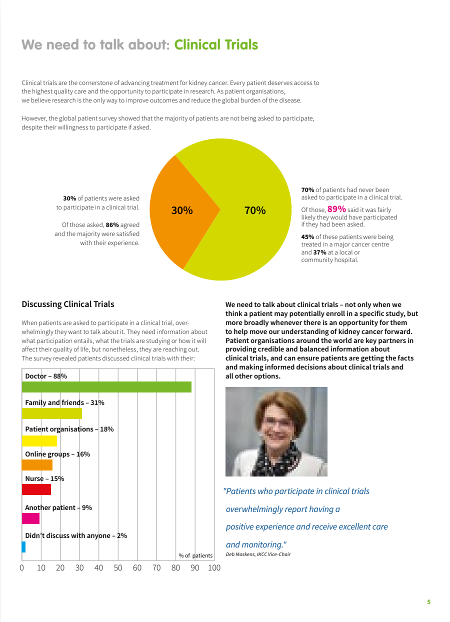
We need to talk about Kidney Cancer.

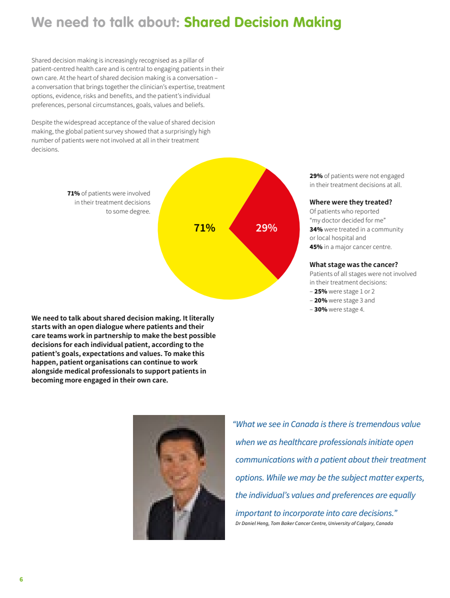

We need to talk about: Kidney Cancer

Demographics


We need to talk about: Knowledge and Understanding


We need to talk about: Quality of Life


We need to talk about: Clinical Trials


We need to talk about: Shared Decision Making


Conclusions and Next Steps

Acknowledgements

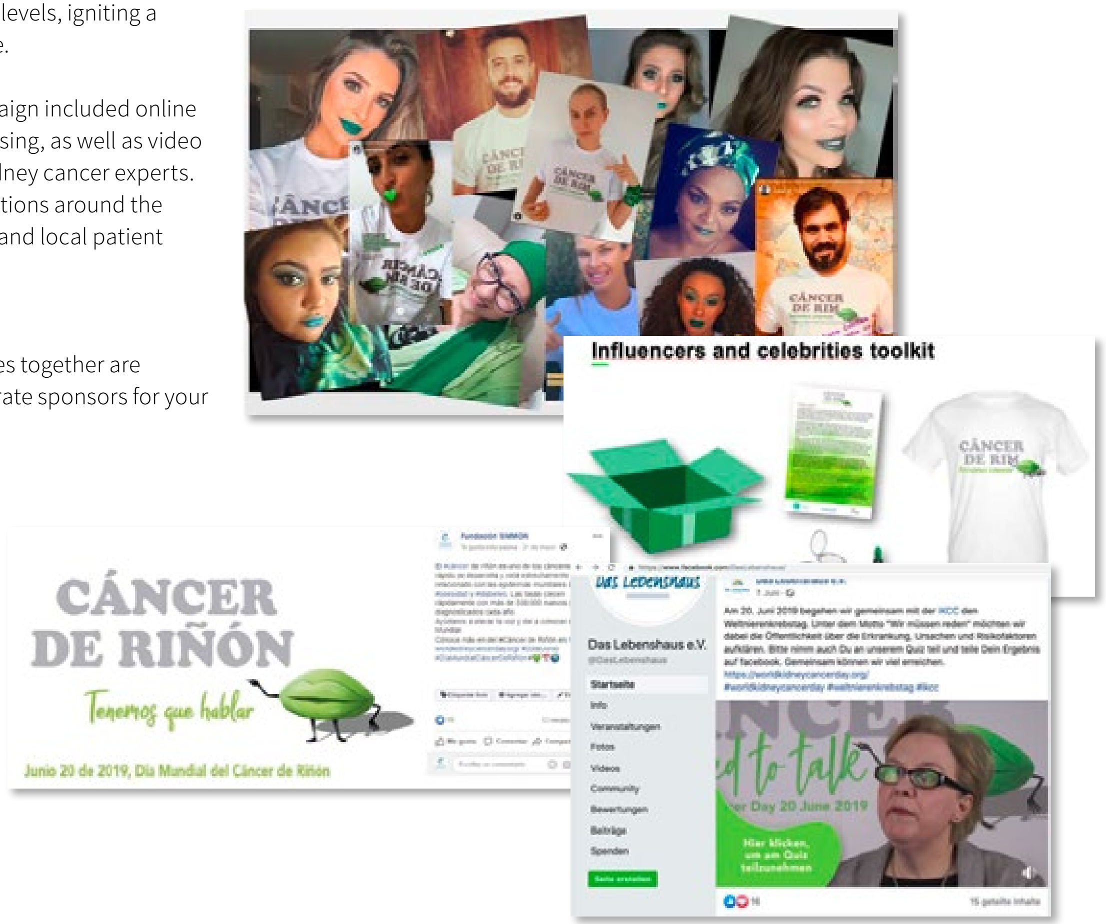
World Kidney Cancer Day 2019

The 3rd World Kidney Cancer Day was celebrated on 20 June 2019 by patients, friends, carers, health professionals, researchers and Affiliate Organisations around the world. The 2019 theme, 'We need to talk', highlighted the urgent need for more awareness and action on kidney cancer around the globe.

Central to World Kidney Cancer Day 2019 was the launch of our landmark Global Patient Survey, which interviewed almost 2,000 patients and carers from 43 countries and uncovered some surprising and alarming data. The survey results continue to spark conversations at many levels, igniting a turning point in global kidney cancer care.

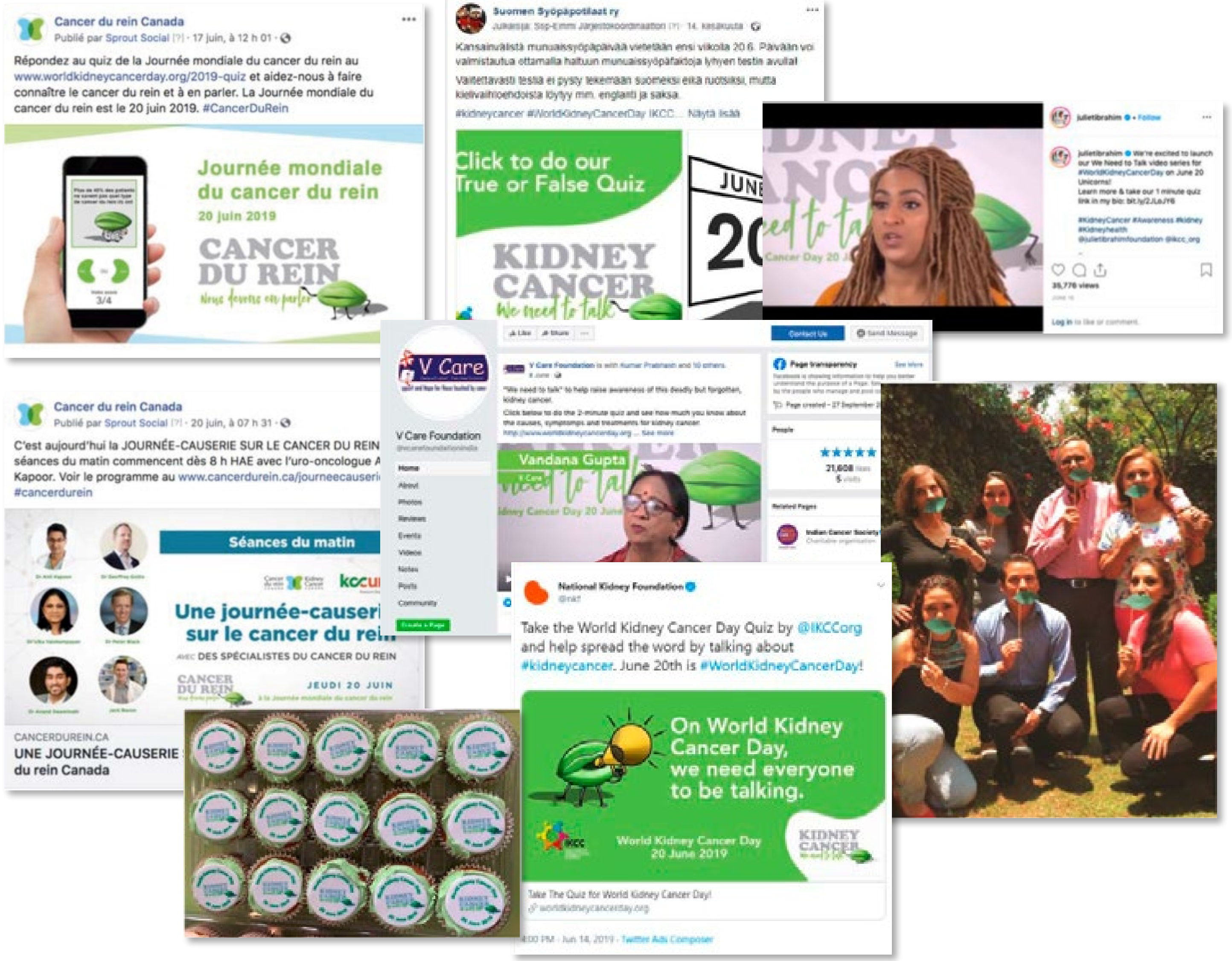
The 2019 World Kidney Cancer Day campaign included online and offline health promotion and advertising, as well as video content from 25 of the world's leading kidney cancer experts. The campaign engaged Affiliate Organisations around the world to advocate for greater awareness and local patient needs.

Thank you to everyone who took part in
World Kidney Cancer Day 2019 – our voices together are stronger! As well, thank you to our corporate sponsors for your support.



Am 20. Juni 2019 begehen wir gemeinsam mit der IKCC den Weltnierenkrebstag. Unter dem Motto "Wir müssen reden" möchten wir dabei die Öffentlichkeit über die Erkrankung, Ursachen und Risikofaktoren aufklären. Bitte nimm auch Du an unserem Quiz teil und teile Dein Ergebnis auf facebook. Gemeinsam können wir viel erreichen.
https://worldkidneycancerday.org/
#worldkidneycancerday #weltnierenkrebstag #ikcc

With a unified commitment to raising awareness, and supporting patient advocacy and research, we will continue our combined efforts to reduce the global burden of kidney cancer!



Cancer du rein Canada
Publié par Sprout Social [?] · 17 juin, à 12 h 01

Répondez au quiz de la Journée mondiale du cancer du rein au www.worldkidneycancerday.org/2019-quiz et aidez-nous à faire connaître le cancer du rein et à en parler. La Journée mondiale du cancer du rein est le 20 juin 2019. #CancerDuRein

Suomen Syöpäpotilaat ry

Kansainvälistä munuaissyöpäpäivää vietetään ensi viikolla 20.6. Päivään voi valmistautua ottamalla haltuun munuaissyöpäfaktoja lyhyen testin avulla!

#kidneycancer #WorldKidneyCancerDay IKCC... Näytä lisää

julietibrahim We're excited to launch our We Need to Talk video series for #WorldKidneyCancerDay on June 20 Unicorns!
Learn more & take our 1 minute quiz link in my bio: bit.ly/2JLaJY6

#KidneyCancer #Awareness #kidney #Kidneyhealth @julietibrahimfoundation @ikcc_org

35,776 views

Log in to like or comment.

Cancer du rein Canada
Publié par Sprout Social [?] · 20 juin, à 07 h 31

C'est aujourd'hui la JOURNÉE-CAUSERIE SUR LE CANCER DU REIN séances du matin commencent dès 8 h HAE avec l'uro-oncologue A Kapoor. Voir le programme au www.cancerdurein.ca/journeecauseri #cancerdurein

CANCERDUREIN.CA
UNE JOURNÉE-CAUSERIE du rein Canada

V Care Foundation

"We need to talk" to help raise awareness of this deadly but forgotten, kidney cancer.
Click below to do the 2-minute quiz and see how much you know about the causes, symptoms and treatments for kidney cancer.

National Kidney Foundation
@nkf

Take the World Kidney Cancer Day Quiz by @IKCCorg and help spread the word by talking about #kidneycancer. June 20th is #WorldKidneyCancerDay!

Take The Quiz for World Kidney Cancer Day!
worldkidneycancerday.org

Jun 14, 2019 · Twitter Ads Composer

My Treatment, My Choice Decision Aid for Small Renal Masses

It is one of IKCC's core beliefs that patients have an essential role to play in healthcare decisions that affect their lives. Involving patients in decisions has become an important aspect of many healthcare systems around the world and has the potential to lead to better health outcomes and improved equity of care.

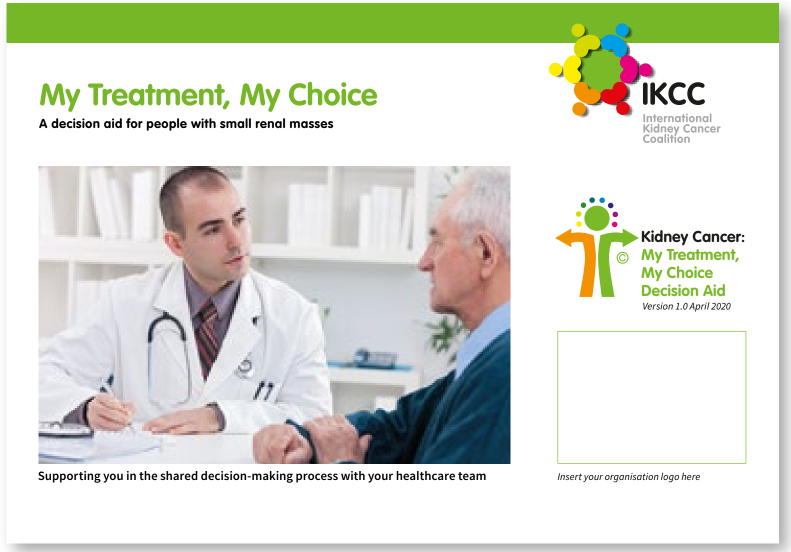
Many treatment decisions for kidney cancer do not have clear answers. They are preference-sensitive and patients are often faced with a bewildering number of treatment options. The IKCC Decision Aid series is written to support patients to make the right decision at the right time. It is important patients are supported both emotionally and practically and an evidence-based comprehensive decision aid written in clear understandable language can provide the confidence and support they need to work with their healthcare team to make the right decisions.

The healthcare decisions facing patients who are newly diagnosed with a small renal mass are numerous and complex. The patient and their family are faced with making crucial decisions at a time when they have little medical knowledge about their situation and are understandably worried about what the future might hold.

That is why in 2019, IKCC commissioned its third RCC Decision Aid, focused on the management of small renal masses (localised RCC) for newly diagnosed patients. It is an impartial presentation of the many options a newly diagnosed patient with a small renal mass should consider, ranging from differing surgical procedures, various ablative procedures or active surveillance.

Research into surgical data was used to inform the decision aid development and patients, medical experts, nurses and academics were invited to form a review panel and provide feedback before publication. The decision aid also includes questions and exercises that prompt patients to explore their personal values, goals and preferences.

The IKCC My Treatment, My Choice Decision Aid for Small Renal Masses follows international standards for patient decision aids (IPDAS: www.ipdas.ohri.ca).



My Treatment, My Choice

A decision aid for people with small renal masses

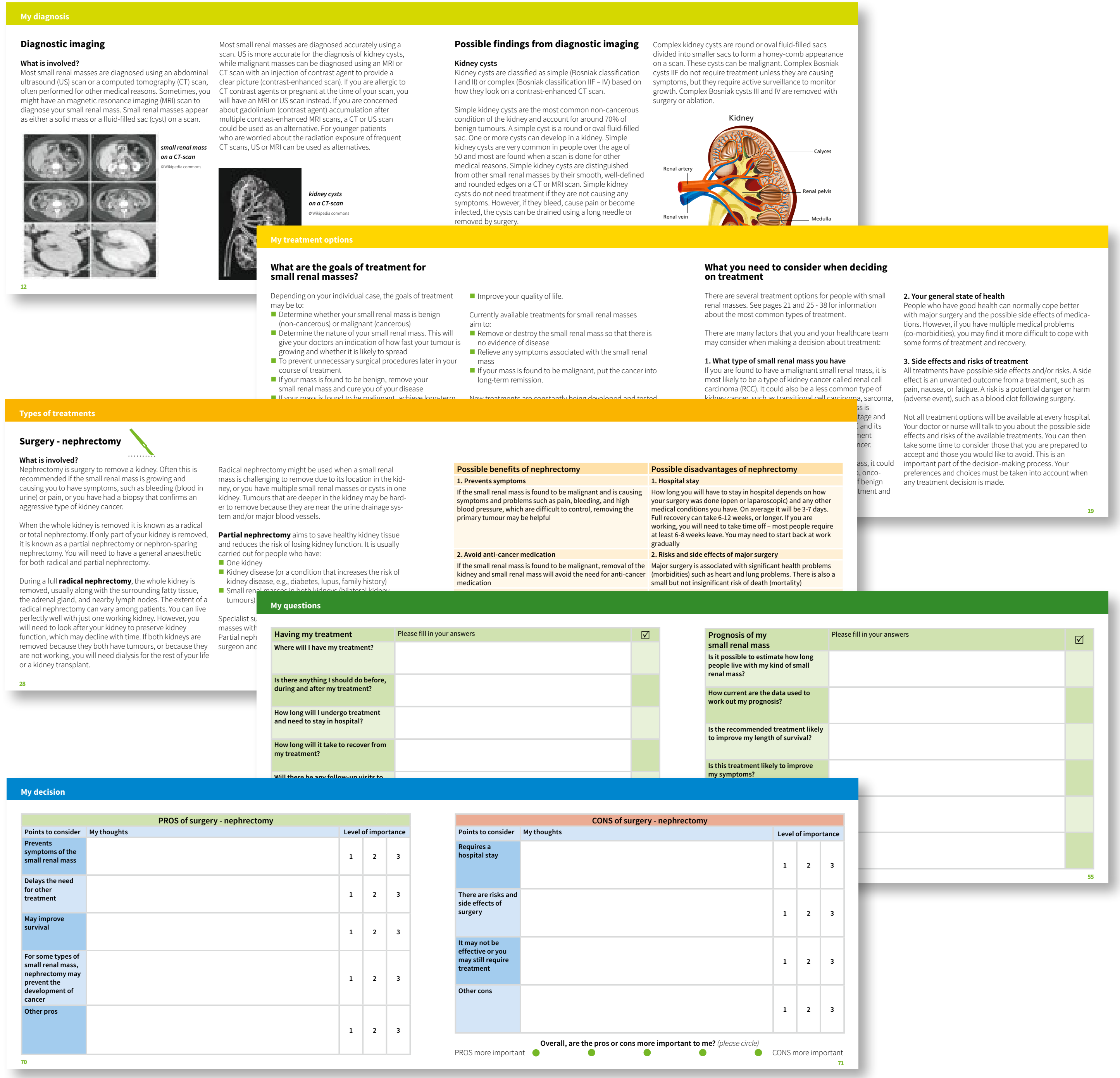
IKCC
International
Kidney Cancer
Coalition

Kidney Cancer:
My Treatment,
My Choice
Decision Aid
Version 1.0 April 2020

Supporting you in the shared decision-making process with your healthcare team

Insert your organisation logo here

Kidney Cancer:
My Treatment,
My Choice
Decision Aid



My diagnosis

Diagnostic imaging

What is involved?
Most small renal masses are diagnosed using an abdominal ultrasound (US) scan or a computed tomography (CT) scan, often performed for other medical reasons. Sometimes, you might have an magnetic resonance imaging (MRI) scan to diagnose your small renal mass. Small renal masses appear as either a solid mass or a fluid-filled sac (cyst) on a scan.

small renal mass on a CT-scan
©Wikipedia commons

Most small renal masses are diagnosed accurately using a scan. US is more accurate for the diagnosis of kidney cysts, while malignant masses can be diagnosed using an MRI or CT scan with an injection of contrast agent to provide a clear picture (contrast-enhanced scan). If you are allergic to CT contrast agents or pregnant at the time of your scan, you will have an MRI or US scan instead. If you are concerned about gadolinium (contrast agent) accumulation after multiple contrast-enhanced MRI scans, a CT or US scan could be used as an alternative. For younger patients who are worried about the radiation exposure of frequent CT scans, US or MRI can be used as alternatives.

kidney cysts on a CT-scan
©Wikipedia commons

Possible findings from diagnostic imaging

Kidney cysts
Kidney cysts are classified as simple (Bosniak classification I and II) or complex (Bosniak classification IIF – IV) based on how they look on a contrast-enhanced CT scan.

Simple kidney cysts are the most common non-cancerous condition of the kidney and account for around 70% of benign tumours. A simple cyst is a round or oval fluid-filled sac. One or more cysts can develop in a kidney. Simple kidney cysts are very common in people over the age of 50 and most are found when a scan is done for other medical reasons. Simple kidney cysts are distinguished from other small renal masses by their smooth, well-defined and rounded edges on a CT or MRI scan. Simple kidney cysts do not need treatment if they are not causing any symptoms. However, if they bleed, cause pain or become infected, the cysts can be drained using a long needle or removed by surgery.

Complex kidney cysts are round or oval fluid-filled sacs divided into smaller sacs to form a honey-comb appearance on a scan. These cysts can be malignant. Complex Bosniak cysts IIF do not require treatment unless they are causing symptoms, but they require active surveillance to monitor growth. Complex Bosniak cysts III and IV are removed with surgery or ablation.

My treatment options

What are the goals of treatment for small renal masses?

Depending on your individual case, the goals of treatment may be to:
- Determine whether your small renal mass is benign (non-cancerous) or malignant (cancerous)
- Determine the nature of your small renal mass. This will give your doctors an indication of how fast your tumour is growing and whether it is likely to spread
- To prevent unnecessary surgical procedures later in your course of treatment
- If your mass is found to be benign, remove your small renal mass and cure you of your disease

- Improve your quality of life.

Currently available treatments for small renal masses aim to:
- Remove or destroy the small renal mass so that there is no evidence of disease
- Relieve any symptoms associated with the small renal mass
- If your mass is found to be malignant, put the cancer into long-term remission.

What you need to consider when deciding on treatment

There are several treatment options for people with small renal masses. See pages 21 and 25 - 38 for information about the most common types of treatment.

There are many factors that you and your healthcare team may consider when making a decision about treatment:

1. What type of small renal mass you have
If you are found to have a malignant small renal mass, it is most likely to be a type of kidney cancer called renal cell carcinoma (RCC). It could also be a less common type of

2. Your general state of health
People who have good health can normally cope better with major surgery and the possible side effects of medications. However, if you have multiple medical problems (co-morbidities), you may find it more difficult to cope with some forms of treatment and recovery.

3. Side effects and risks of treatment
All treatments have possible side effects and/or risks. A side effect is an unwanted outcome from a treatment, such as pain, nausea, or fatigue. A risk is a potential danger or harm (adverse event), such as a blood clot following surgery.

Not all treatment options will be available at every hospital. Your doctor or nurse will talk to you about the possible side effects and risks of the available treatments. You can then take some time to consider those that you are prepared to accept and those you would like to avoid. This is an important part of the decision-making process. Your preferences and choices must be taken into account when any treatment decision is made.

Types of treatments

Surgery - nephrectomy

What is involved?
Nephrectomy is surgery to remove a kidney. Often this is recommended if the small renal mass is growing and causing you to have symptoms, such as bleeding (blood in urine) or pain, or you have had a biopsy that confirms an aggressive type of kidney cancer.

When the whole kidney is removed it is known as a radical or total nephrectomy. If only part of your kidney is removed, it is known as a partial nephrectomy or nephron-sparing nephrectomy. You will need to have a general anaesthetic for both radical and partial nephrectomy.

During a full **radical nephrectomy**, the whole kidney is removed, usually along with the surrounding fatty tissue, the adrenal gland, and nearby lymph nodes. The extent of a radical nephrectomy can vary among patients. You can live perfectly well with just one working kidney. However, you will need to look after your kidney to preserve kidney function, which may decline with time. If both kidneys are removed because they both have tumours, or because they are not working, you will need dialysis for the rest of your life or a kidney transplant.

Radical nephrectomy might be used when a small renal mass is challenging to remove due to its location in the kidney, or you have multiple small renal masses or cysts in one kidney. Tumours that are deeper in the kidney may be harder to remove because they are near the urine drainage system and/or major blood vessels.

Partial nephrectomy aims to save healthy kidney tissue and reduces the risk of losing kidney function. It is usually carried out for people who have:
- One kidney
- Kidney disease (or a condition that increases the risk of kidney disease, e.g., diabetes, lupus, family history)

Possible benefits of nephrectomy	Possible disadvantages of nephrectomy
1. Prevents symptoms	**1. Hospital stay**
If the small renal mass is found to be malignant and is causing symptoms and problems such as pain, bleeding, and high blood pressure, which are difficult to control, removing the primary tumour may be helpful	How long you will have to stay in hospital depends on how your surgery was done (open or laparoscopic) and any other medical conditions you have. On average it will be 3-7 days. Full recovery can take 6-12 weeks, or longer. If you are working, you will need to take time off – most people require at least 6-8 weeks leave. You may need to start back at work gradually
2. Avoid anti-cancer medication	**2. Risks and side effects of major surgery**
If the small renal mass is found to be malignant, removal of the kidney and small renal mass will avoid the need for anti-cancer medication	Major surgery is associated with significant health problems (morbidities) such as heart and lung problems. There is also a small but not insignificant risk of death (mortality)

My questions

Having my treatment	Please fill in your answers	☑
Where will I have my treatment?		
Is there anything I should do before, during and after my treatment?		
How long will I undergo treatment and need to stay in hospital?		
How long will it take to recover from my treatment?		

Prognosis of my small renal mass	Please fill in your answers	☑
Is it possible to estimate how long people live with my kind of small renal mass?		
How current are the data used to work out my prognosis?		
Is the recommended treatment likely to improve my length of survival?		
Is this treatment likely to improve my symptoms?		

My decision

PROS of surgery - nephrectomy				
Points to consider	My thoughts	Level of importance		
Prevents symptoms of the small renal mass		1	2	3
Delays the need for other treatment		1	2	3
May improve survival		1	2	3
For some types of small renal mass, nephrectomy may prevent the development of cancer		1	2	3
Other pros		1	2	3

CONS of surgery - nephrectomy				
Points to consider	My thoughts	Level of importance		
Requires a hospital stay		1	2	3
There are risks and side effects of surgery		1	2	3
It may not be effective or you may still require treatment		1	2	3
Other cons		1	2	3

Overall, are the pros or cons more important to me? *(please circle)*

PROS more important ● ● ● ● ● CONS more important

Global Kidney Cancer Dashboard

IKCC is developing a Global Dashboard to enhance access to information on treatment options and places to receive care for kidney cancer. This resource provides information on available therapies, clinical trials, and centres providing treatment for patients with kidney cancer.

Initial efforts are focused on Latin America, but ultimately this resource will cover the entire world. Country-specific data will be obtained and maintained in collaboration with Affiliate Organisations, patients and physician groups.

The interface is easy to navigate, starting with a world map that allows one to select a country. Country-specific data becomes available and key centres identified as providing kidney cancer care are indicated on the map with pushpins. Clicking on the pushpins will reveal additional information on each centre.

The Global Kidney Cancer Dashboard will improve the lives of patients with kidney cancer with easy-to-access information and will empower Affiliate Organisations and physicians caring for patients with kidney cancer worldwide.

A.C.Camargo Cancer Center

Rua Professor Antonio Prudente, 211

Website: https://www.accamargo.org.br/

Radical nephrectomy	✓
Partial nephrectomy	✓
Robotic nephrectomy	✓
Radiofrequency ablation	✓
Cryoablation	✓
Conventional external beam	✓
Stereotactic radiosurgery	✓
Active surveillance	✓
Immunotherapy	✓
Targeted therapy	✓

Clinical Trials: Spreading the Word around the World

Clinical trials provide many patients around the world with opportunities to participate in the latest research in kidney cancer. In many countries, patients can consider a clinical trial at each decision point in their treatment journey. In other countries, however, even with significant numbers of kidney cancer patients, there are few clinical trials available and even fewer resources to access those trials.

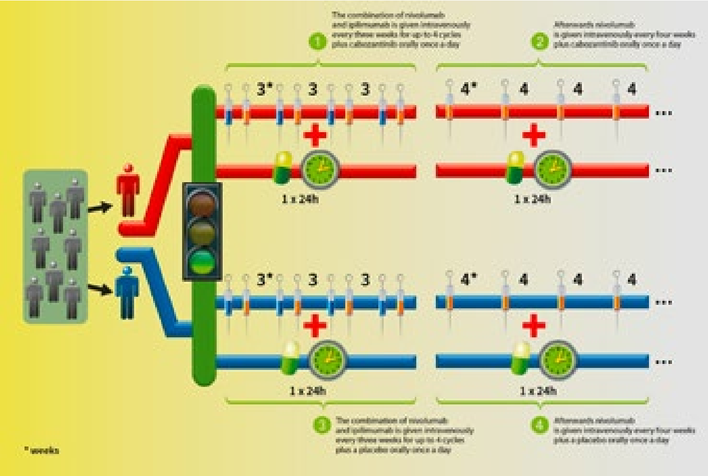
For large clinical trials, particularly those with truly a global reach, IKCC aims to communicate what the trial opportunity is, which countries are participating, and in lay terms, what the clinical trial involves.

Our Clinical Trial Search allows patient organisations in any country to quickly and easily identify which trials are currently open for patient recruitment. For global trials, we also provide a lay summary and an easy-to-follow graphic that patient organisations can translate and share with their community.

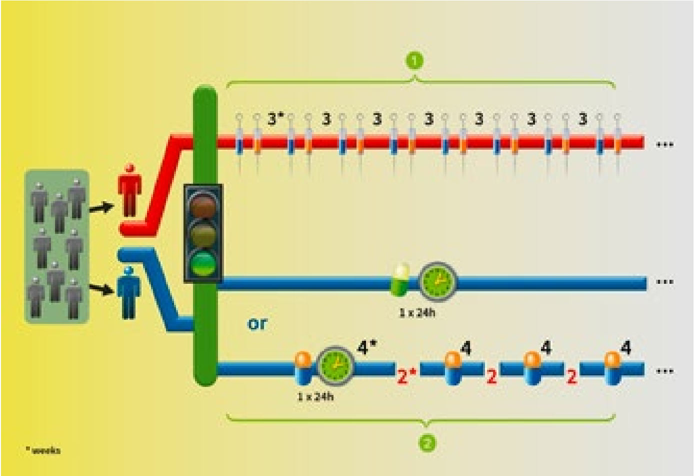
Examples of two ongoing global clinical trials include:

- COSMIC 313 – a Phase 3 trial for metastatic kidney cancer, recruiting patients from South America, North America, Europe and Asia
- NKTR-214 Combination – a Phase 3 trial for metastatic kidney cancer patients, recruiting in Australia, New Zealand, USA, South America, and Asia

COSMIC 313



NKTR-214



IKCC Global Kidney Cancer Summit 2019

Lisbon, Portugal

IKCC Global Kidney Cancer Summit 2019

IKCC
Global
Kidney Cancer
Summit

IKCC welcomed over 50 patient advocates from 26 countries and six continents to the 9th Global Kidney Cancer Summit in Lisbon, Portugal, including new participants from Africa, Asia, Europe and North America.

The Summit is held annually and brings together the global kidney cancer community to:

- Update the patient advocate community with new developments in the rapidly-changing field of kidney cancer – from diagnosis to the treatment of advanced disease
- Learn from one another and build new skills in key areas for patient involvement including research, clinical trials, guidelines development and real-world evidence
- Build new partnerships, stimulate networks, and foster and develop a strong role for patient advocacy in kidney cancer globally

The 2019 Summit highlighted IKCC's value of connecting patient groups and collaborating with healthcare professionals and the healthcare industry.

Throughout the three-day event, medical experts and patient leaders shared expertise and experiences, with topics ranging from new treatment approaches in kidney cancer to the launch of patient support and disease awareness programs. Capacity Building Workshops encouraged delegates to participate in interactive learning sessions on various areas of importance including traditional and social media communications, patient surveys, survivorship and grant writing.

For a complete summary of the Global Kidney Cancer Summit 2019, visit the IKCC website.

Expanding Partnerships
for Patients Worldwide

IKCC
Global
Kidney Cancer
Summit
2019

9th International Conference
for Organisations
Representing Patients
With Kidney Cancer
4th – 6th April
Tivoli Oriente Lisboa Hotel,
Portugal

Conference
Booklet



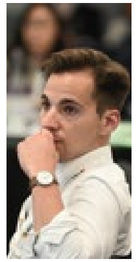


















IKCC Global Kidney Cancer Summit 2019




















IKCC
International Kidney Cancer Coalition
KIDNEY CANCER
by Kidney Canc

IKCC Global Kidney Cancer Summit 2019





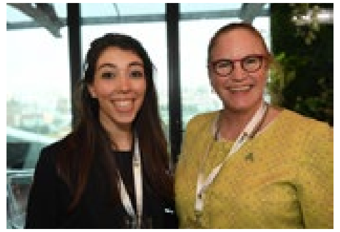













IKCC Global Kidney Cancer Summit 2019
















Treasurer's Report 2019

It gives me great pleasure to present our Annual Financial Overview for 2019. The Board has worked consistently with our accounting team and auditors to deliver the audited financial statements that indicate the IKCC is in a healthy and well-managed financial position with funds appropriately allocated to projects that fulfil the IKCC mission and vision.

The financial position of IKCC has continued to improve in 2019 enabling greater levels of advocacy for better health outcomes around the globe, delivery of our annual Global Kidney Cancer Summit, promotion of World Kidney Cancer Day globally and ongoing liaison with and support for the efforts of Affiliate Organisations and emerging organisations internationally.

Van Hoesel De Blaey Accountancy B.V. of Rotterdam in the Netherlands have worked with the Board and management to deliver independently audited financial statements that will be presented at the IKCC Annual General Meeting in 2020.

In accordance with Dutch audit law, we report there have been no changes to the IKCC by-laws in the last calendar year and the Board has designated that IKCC reserves be earmarked for the following projects that enable us to deliver on our business objectives, mission and vision:

- Euro 116,000 Global Kidney Cancer Summit 2020
- Euro 120,000 World Kidney Cancer Day 2020
- Euro 85,000 Global Patient Survey
- Euro 44,000 Dashboard Project

The Board has estimated that Euro 100,000 should be kept in the organisations' free reserves to cover yearly recurring overhead expenses.

We are grateful to our Sustaining Partners whose support of our work allows us to deliver a full range of critical projects on behalf of IKCC's Affiliate Organisations and people with or affected by kidney cancer worldwide.

We thank all those who have enabled IKCC to spread its messages of courage and hope around the world. With your support, IKCC will continue to expand its reach globally in 2020 and beyond.

Anne Wilson
Secretary-Treasurer
IKCC Board

2019 Financial Statements

These figures are extracted from the complete annual report 2019 of Stichting International Kidney Cancer Coalition in Ouder-Amstel as determined by the Board on February 28, 2020. This annual report has been provided with an unqualified auditor's report, under condition that the corresponding figures included in the profit and loss account, in the statements of changes and in the related notes were not audited because the annual accounts 2018 were not audited by Van Hoesel De Blaey Accountancy B.V. To view the 2019 Financial Statements please visit the IKCC website: www.ikcc.org

Independent Auditor

Van Hoesel De Blaey Accountancy B.V.
Brouwerstraat 6
3364 BE
Sliedrecht
The Netherlands

Financial Services

Administratiekantoor Boekjewinst.nl BV,
Computerweg 22,
3542DR Utrecht,
The Netherlands

IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2019		
CURRENT ASSETS		
Other prepayments and accrued income	**€**	**67,210**
Liquid assets	**€**	**667,995**
TOTAL CURRENT ASSETS	**€**	**735,205**
CURRENT LIABILITIES		
Creditors and borrowings	**€**	**38,121**
Accrued liabilities	**€**	**125,384**
TOTAL CURRENT LIABILITIES	**€**	**163,505**
NET ASSETS	**€**	**571,700**
ACCUMULATED FUNDS		
Reserves	**€**	**194,463**
Last year surplus/(deficit)	**€**	**231,246**
Current year surplus/(deficit)	**€**	**145,991**
TOTAL ACCUMULATED FUNDS	**€**	**571,700**

Joining IKCC

Under the Constitution of the International Kidney Cancer Coalition, organisations may apply for Affiliate status.

AFFILIATED ORGANISATION of IKCC
International Kidney Cancer Coalition

AFFILIATE ORGANISATION

Affiliate Organisations are registered patient organisations that meet the following criteria:

- Has a focus on providing services and/or supporting patients with kidney cancer and raising awareness, promoting research, or empowering organisations that are focused on supporting those affected by kidney cancer.
- Is recognised and/or registered as a non-profit organisation.
- Is willing to abide by the IKCC Code of Conduct in addition to adhering to the strict ethical guidelines for charities and non-profits according to their own national contexts.
- Is willing to work with and co-operate with other organisations having the same objectives.

SUPPORTER

Supporters interested in the work of IKCC, may include organisations who do not yet fulfill the criteria of an Affiliate Organisation, or are individuals with an interest in kidney cancer who may wish to attend future meetings or join our mailing list.

Supporters include individuals who may be strongly motivated to start kidney cancer groups in their own countries.

Supporters are kept informed of activities of the IKCC but have no voting rights.

Please see the IKCC website for further information:
www.ikcc.org/about-ikcc/join-the-network/

New Affiliate Organisations in 2019

Czech Republic:
Onkomaják
www.onkomajak.cz

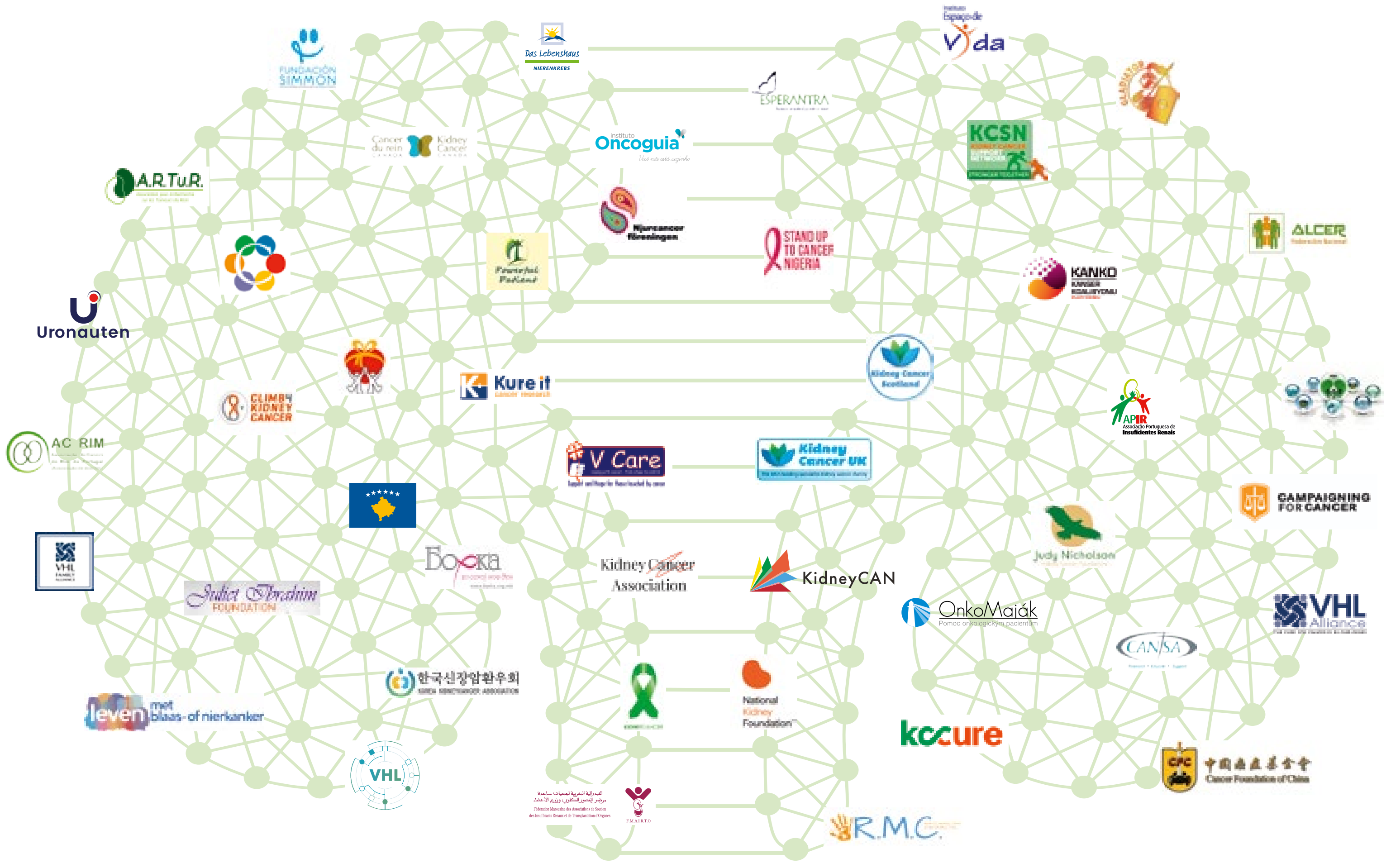
South Africa:
Campaigning for Cancer
www.campaign4cancer.co.za

South Korea:
Korea Kidney Cancer Association
www.kidneycancer.co.kr

Sweden:
Kidney Cancer Association of Sweden
www.njurcancerforeningen.se

USA:
Kidney Cancer Association (KCA)
www.kidneycancer.org

USA:
National Kidney Foundation
www.kidney.org



IKCC Affiliate Organisations

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.

AFFILIATED
ORGANISATION
of
IKCC
International
Kidney Cancer
Coalition

IKCC 2019: Board Members

RACHEL GILES,
MD, PhD (IKCC Chair)
Von Hippel-Lindau
Organisation / Living with
Bladder or Kidney Cancer
Netherlands

Dr Rachel Giles has experience as Associate Professor of Internal Medicine at the University Medical Center Utrecht in the Netherlands and is the Science Officer and Medical Education Specialist at Medicom Medical Publishers in Baarn, the Netherlands. She has been active in advocacy for patients with inherited kidney cancer since 2003 and has been chair of the Dutch VHL Organisation since 2009. Rachel is Chair of IKCC and represents IKCC on the EAU Guidelines Committee for renal cell carcinoma.

DEBORAH MASKENS,
M. A., M.S.M.
(IKCC Vice Chair)
Kidney Cancer Canada,
Canada

As co-founder of Kidney Cancer Canada, Deb Maskens has worked to ensure access to high-quality care for patients across Canada. A long-time kidney cancer patient herself, she has spoken at national and international cancer meetings combining the patient perspective along with sound advocacy knowledge and experience. For her role in establishing Kidney Cancer Canada, Deb was recognised with the Meritorious Service Medal by Canada's Governor General, the Queen's representative in Canada. She serves as a Patient Advocate on the National Cancer Institute Renal Task Force. Deb is a founding member of IKCC.

BERIT EBERHARDT
Uronauten e.V., Germany

Berit Eberhardt has been connected to kidney cancer since 2009, following her partner's diagnosis with papillary type II renal cell carcinoma. To support him she researched the disease and its treatment. Knowing the needs of patients and caregivers in the same situation, she established a patient support group and became an advocate for kidney cancer patients after her partner died. Being a cancer survivor herself, she is committed to bringing the patient perspective into various projects and publications (e.g. the German RCC guidelines and scientific publications). Berit has been involved with IKCC since 2010.

MICHAEL A.S. JEWETT,
MD, FRCSC, FACS
Canada

Dr Michael Jewett Professor of Surgery (Urology) at Princess Margaret Cancer Centre and the University of Toronto. He was an enthusiastic supporter of the founding of Kidney Cancer Canada and was the founding and immediate past-Chair of the Kidney Cancer Research Network of Canada.
Dr Jewett was awarded the Canadian Cancer Research Alliance Award for Exceptional Leadership in Patient Involvement in Cancer Research in 2017 and serves as Surgical Co-Chair on the USA National Cancer Institute's Renal Task Force. He has published more than 350 peer-reviewed papers and has a long-time interest in many aspects of kidney cancer research, patient care and knowledge transfer. A leader in academic urology,
Dr Jewett is a frequent guest at urological association meetings and has been a Visiting Professor in 25 countries at more than 100 university departments and institutions.

ERIC JONASCH, MD
Professor of Medicine
USA

Dr Eric Jonasch is Professor in the Department of Genitourinary Medical Oncology at the University of Texas MD Anderson Cancer Center in Houston, Texas. He performs clinical, translational and basic research in kidney carcinoma and VHL disease. Dr Jonasch has authored over 200 articles published in peer-reviewed journals and is editor of the textbook: Kidney Cancer, Principles and Practice. Dr Jonasch has a long history of service in the kidney cancer community. He serves as Vice-Chair of the National Comprehensive Cancer Network's Kidney Cancer Guideline Panel, is a member of the U.S. National Cancer Institute Renal Task Force and is a Board member of the VHL Alliance.

BRYAN LEWIS, J.D.
KidneyCAN, USA

Bryan Lewis has led the advocacy and Research Summit efforts for KidneyCAN (www.kidneycan.org). As a kidney cancer survivor, he has been an active legislative advocate and policy spokesman for the kidney cancer community in Washington, D.C. devoting most of his efforts to policy advocacy. Most recently, he helped spear-head a community effort to obtain $40 million annually for the Kidney Cancer Research Program (www.cdmrp.army. mil/kcrp/). Bryan has also been appointed to the National Comprehensive Cancer Network's Kidney Cancer Guidelines Panel. Previously, he held the positions of Vice President, Operations for Brand USA, and as Chief of Staff & General Counsel, U.S. Travel Association.

ANNE WILSON

Anne Wilson & Associates, Australia

Formerly CEO and Managing Director of Kidney Health Australia – Anne Wilson has been a member of the IKCC Board for the last four years. Since stepping down as CEO in May 2016, she has consulted to a number of not-for-profit organisations in Australia. Anne pioneered Kidney Health Australia's work in advocacy and support for Australians and families affected by kidney cancer and oversaw the development of resources, a website, telephone information service and promotion of information about access to relevant clinical trials in Australia. As a Social Worker, Anne is passionate about equitable access to service delivery and the latest and most up-to-date information about kidney cancer and patient support. Anne is Secretary/Treasurer of IKCC and has been the Board lead for the management of World Kidney Cancer Day since its inception.

ROSE WOODWARD

Kidney Cancer Support Network, UK

Rose Woodward is a patient survivor of kidney cancer and a passionate and active patient advocate. She became involved in advocacy and patients' rights in 2006 when she led the successful "Fight for Life" campaign for kidney cancer drug treatments in the United Kingdom. Rose and her team manage the Kidney Cancer Support Network charity aimed at empowering patients to be full partners in their care and treatment and also served 10 years at the UK National Cancer Research Institute working to establish patient involvement in all areas of research. Rose is a founding volunteer member of the IKCC Board.

Acknowledgements

The IKCC Board is committed to open and transparent partnerships with the healthcare industry in accordance with our Code of Conduct (www.ikcc.org) and international standards. Achieving balanced and multi-sourced funding helps us meet our goal of collaborating with all stakeholders including patient organisations, medical experts, and the healthcare industry. Such funding allows our organisation to focus on our mission – to reduce the global burden of kidney cancer.

We thank the following funders who have supported IKCC in 2019 with Sustaining Partnerships and Project Sponsorships.

Sustaining Partners (2019)

Bristol Myers Squibb™ EXELIXIS® MERCK*

MSD INVENTING FOR LIFE NOVARTIS Pfizer

Project Sponsors (2019)

Bristol Myers Squibb™ IPSEN Innovation for patient care MERCK

NOVARTIS Pfizer Roche

*Partial Funding

IKCC Annual Report 2019 – Imprint:

Text: IKCC Board and Julia Black (UK)
Graphic Design: Herbert Thum, www.VISKON.de, (DE)
Photos: Uli Deck, ARTIS, Fotolia, Adobe Stock

IKCC
International
Kidney Cancer
Coalition

International Kidney Cancer Coalition

Registered Office:
't Ven 30
1115HB Duivendrecht,
The Netherlands
Email: info@ikcc.org
Website: www.ikcc.org
www.worldkidneycancerday.org

Search for us on Facebook as: ikcc

Follow us on Twitter: @IKCCorg
@IKCCtrials

Registered in the Netherlands under:
Stichting IKCC
Reg.-No. KvK 62070665