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

Annual Report 2019
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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 psychosocial 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 organisational 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.

The VALUES of IKCC

- Innovative
- Professional
- Culturally sensitive (respectful)
- Collaborative but independent
- Patient centred and democratic
- Ethical
- Transparent
- Professional
2019: IKCC by the Numbers

- **Projects and Activities 2019**
- **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
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 (IPOC), 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 experiences 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.

We need to talk about Kidney Cancer.

We need to talk about: Knowledge and Understanding

We need to talk about: Clinical Trials

We need to talk about: Shared Decision Making

We need to talk about: Quality of Life

Fact box

- The Global Patient Survey to track progress, analyse trends, and delve more deeply into areas of inquiry most important to the kidney cancer patient community.
- The survey was conducted in 2018 and included 1,983 patients and carers from 43 countries.
- The survey results were presented at various conferences, including the IKCC Global Summit in Portugal and the Canadian Kidney Cancer Research Network Conference in Canada.
- The results provided high-quality evidence for improving kidney cancer patients' experiences.

Demographics

- The survey included respondents from Canada (12%), Spain (18%), and the United States (28%).
- The majority of respondents were between the ages of 50 and 69 years.

Health outcomes

- The most common conditions included:
  - Metastatic kidney cancer (44%)
  - Disease-related anxiety (60%)
  - Family and friends (31%)
- Other conditions included:
  - General anxiety (31%)
  - Risk of recurrence (28%)
  - Treatment decisions (45%)
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.

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!
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 on several drafts.

The IKCC My Treatment, My Choice Decision Aid for Small Renal Masses (IPDAS: www.ipdas.ohri.ca).
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-access information and will empower Affiliate Organisations and physicians caring for patients with kidney cancer worldwide.
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 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.
Financial Overview

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 fulfill 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:

- €116,000 Global Kidney Cancer Summit 2020
- €120,000 World Kidney Cancer Day 2020
- €85,000 Global Patient Survey
- €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

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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.

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.

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
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.
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 Mentors 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.

BERT EBERHARDT
Uronauten e.V., Germany

Bent 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). Bent has been involved with IKCC since 2010.

MICHAEL A.S. JEWETT, MD, FRCS, 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 spokesperson for the kidney cancer community in Washington, D.C. devoting most of his efforts to policy advocacy. Most recently, he helped spearhead 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)

Project Sponsors (2019)

*Partial Funding
International Kidney Cancer Coalition

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Follow us on Twitter: @IKCCorg
@IKCCTrials

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