



Global Kidney Cancer Summit

18th – 20th June 2023
Buenos Aires, Argentina

Day 1

Welcome to the 2023 Global Kidney Cancer Summit

Dr Michael Jewett, IKCC Chair (CA)

Dr Rachel Giles, IKCC CEO (NL)

Dr Claudia Miranda, VICARE (AR)

Dr Michael Jewett, Chair of the IKCC Board, and Dr Rachel Giles, CEO of the IKCC, welcomed everyone to the 13th IKCC Global Kidney Cancer Summit. The main goals of the conference were to support patient advocates in developing new knowledge and skills about the diagnosis and treatment of kidney cancer, identify common needs, problems, and challenges, and share ideas, best practices, and solutions to enhance their work.

Dr Giles welcomed one of our new affiliates who are hosting this year's summit; the Argentine organisation VICARE Kidney Cancer Patient Support Group.

Dr Claudia Miranda welcomed everyone to Argentina and introduced VICARE. VICARE is the first Argentinian association for kidney and bladder cancer patients and relatives. VICARE's aim is to reduce mortality associated with kidney and bladder cancer and to support patients and their relatives. They do this through education, prevention, support, raising awareness and research. They run awareness programmes on the prevention of kidney cancer for the public since kidney cancer is the fifth most prevalent cancer in Argentina. They focus on healthy treatment, trying to combine nutrition, physical activity, medical treatment, and psychological coaching for patients and their families. They have created the VICARE community, a database of patients needing support. They also offer patient conferences, general counselling, research, a newsletter, social media, free creative activities, artistic workshops, employment counselling for patients, and cancer prevention programmes.

On World Kidney Cancer Day on 15 June, they held their first virtual symposium, which is available to view on their website. They also carried out an Awareness Walk.

VICARE was founded by Dr Claudia Miranda and her husband three years ago, with support from Dr Matías Chacón, honorary President of VICARE and head of the Department of Oncology, Instituto Alexander Fleming, Buenos Aires. Dr Miranda feels it is important to create global networks to support each other. VICARE are thankful to be part of IKCC and to be at the Global Kidney Cancer Summit to help people living with kidney cancer together.

Patient group meet and greet

Moderators: Christine Collins, Kidney Cancer Canada (CA) and Liz Leff, National Kidney Foundation (US)

Attendees introduced themselves, the organisation they were representing, and shared their objectives for attending the summit. Key themes for objectives included advancing their knowledge about kidney cancer and treatment, learning how to better support kidney cancer patients and their carers, sharing with other organisations the challenges they are facing, sharing best practices, and networking with other organisations around the world.

Making ourselves heard

Moderator: Dena Battle, KCCure (US)

Panellist (virtual): Dr Brian Rini, Associate Professor of Medicine (genitourinary cancer), Vanderbilt University, Nashville, TN, USA

Panellist: Lauren Pretorius, Campaigning for Cancer (ZA)

Panellist: Jyoti Patil Shah, V Care Foundation (IN)

Panel discussion about barriers to accessing kidney cancer care

In low-middle income countries, barriers to accessing kidney cancer care include poor health literacy resulting in a late diagnosis, transportation issues that prevent patients from attending treatment centres, infrastructure issues, and funding.

In India, 70% of the population is rural and many are unable to afford travel to the cities for treatment. In South Africa, people with health insurance have good access to care, but those on low incomes have poor access. The poor tend to be less educated, with low health literacy, and do not present to their doctor until the cancer is advanced. When they present to their doctor, they often have trouble explaining their symptoms because of language barriers, health literacy, and the stigma of cancer, leading to further delays in access to treatment.

Patients in low-middle income countries cannot afford to take time off work to get a diagnosis and treatment. They are also unable to work because they are sick, and unable to support their families. They can lose their jobs because they take time off work to attend treatment centres or because they are sick. These issues also occur in Western countries, but to a lesser extent. Telehealth could be a solution to the transportation issues. Good communication with patients can help improve health literacy. Access issues are very country specific, e.g., in India it can take up to 4 days to travel to reach treatment centres. There is also a lack of technology in low-middle income countries.

In upper-middle income countries, there is inability to recruit for clinical trials and low population diversity in clinical trials. Engagement with clinical trials needs to improve across countries to increase diversity. The more genetically diverse the clinical trial population, the more opportunity for discovering something new. In upper-middle income countries, travel to clinical trial sites is a problem. We need novel technologies to make clinical trial participation easier e.g., telehealth to save on travel time and cost.

Motivation for patients in low-middle income patients is high, especially if they have families to support. However, their environment and circumstances prevent them from attending treatment centres. If things are made easier for them, their motivation will stay. In India, policy makers, pharma and patient organisations can help make things easier for the patients. Patient organisations are proactive in understanding the patients' needs. They work with policy makers and government in understanding patient needs. Dr Rini and Dena Battle closed the session by thanking the panellists for their shared experiences and insights.

Solutions

Immunotherapy is expensive and administered as an intravenous infusion, requiring travel to treatment centres every 2-3 weeks. To reduce travel time and cost, patients can be prescribed oral targeted therapies that can be taken at home. However, immunotherapy improves survival and can result in durable remissions. Clinical trials may be an avenue for access to immunotherapy. There is a study evaluating pembrolizumab administered as an injection through the skin (subcutaneous) and taken at home.

Many patients in low-middle income countries can't access immunotherapy because of the high cost. In India, only the very rich can access these drugs – the poor are prescribed generic drugs. Globally, we need better access to immunotherapies for all patients.

In India, patient groups work with pharma companies to develop access programmes. They run awareness campaigns via social media, such as the World Kidney Cancer Day, to help people better understand kidney cancer and treatments. Global coalitions, such as the IKCC and physician societies/associations can give patient advocacy a global voice, which will be heard by the decision-makers and other countries will take notice.

There was a question from the audience about programmes to incentivise patients to attend medical appointments. We shouldn't have to incentivise people to look after their own health, we need to address the health care system to make it easier for patients to access care.

In South Africa, [Campaigning for Cancer](#) provides patients with an app that enables them to pay for transport to hospital. They must follow the legal routes to access treatment and are unable to incentivise patients.

In Malawi, the [World Child Cancer UK](#) charity and the WHO have a Zero Abandonment Programme for children with cancer. There is a high mortality rate because parents are taking children out of treatment because they cannot afford to stay with their children. The parents are provided with funds to allow them to stay with their children and mortality rate has decreased. This would be difficult to implement for adults.

In India, patients are contacted by a patient navigator to find out why they didn't attend their hospital appointment and to help solve their problems. This increases hospital attendance. A treatment stipend is also provided by the government through social programmes.

Sharing best practices

Moderator: Jyoti Patil Shah, V Care Foundation (IN)

Participation for better care

Jin Young Paik, Korea Kidney Cancer Association (KR)

Jin Young Paik from the [Korea Kidney Cancer Association \(KKCA\)](#) gave a summary of their work to improve the care and treatment of patients using online and in person strategies. They use an app for kidney cancer patients and families to come together to share experiences for mutual support. All members are vetted to ensure they are real patients. KKCA bridges the gap between patient and healthcare team. They provide a counselling service, and small group activities for companionship. Through counselling they provide treatment advice and support. They also address issues, such as access to medicines, and provide expert advice to empower patients and enhance care and treatment.

Using the KKCA app and the counselling service, they build patient trust in the organisation. This allows patients to be informed and engaged, creating a strong sense of connection among members. Members feel empowered to contribute and support each other. They use Facebook to encourage participation in the online community. However, older patients are fearful of social media, so they reach out to them directly to create a supportive environment to make each individual feel valued.

Supporting kidney cancer patients in Mexico

Carlos Castro, Asociación ALE (MX)

Carlos Castro spoke about the activities of [Asociación ALE](#) to support patients in Mexico. Asociación ALE provide social assistance for transplant and cataract surgeries to people on low income without social security. They help improve the culture for organ and tissue donation, influence public policies, and provide support materials for patients and their families. They work at the national level. To date, they have provided financial support for 1,394 transplants, mostly kidney transplants. They provide patient education through TV, press, webinars and conferences, and campaign about general health. They donate funds for health services and scholarships, e.g.,

ultrasound equipment, kidney dialysis etc. They hold kidney cancer press conferences with media and kidney cancer experts to discuss health challenges, patient roles, and public policies where they represent the patient voice.

Support and education for urological cancers in Poland

Katarzyna Teodorczyk & Tadeusz Włodarczyk, Association Gladiator (PL)

Gladiator was established in 2002 to support prostate cancer patients in Poland. Since then, they have grown to provide support and education for all urological cancers, including kidney cancer. They provided printed materials that are distributed across Poland by volunteers. They educate patients and families in early diagnosis and prevention. They have a telephone helpline for mutual support and advice. They also have a website containing basic information about kidney cancer. However, elderly patients prefer printed materials. They organise symposia with kidney cancer experts and patients. These are very popular with 2-300 patients joining.

Adjuvant therapy decision aid tool

Christine Collins, Kidney Cancer Canada (CA)

Christine Collins presented Kidney Cancer Canada's decision aid for adjuvant therapy. Adjuvant therapy is anti-cancer medication that is given after surgery to stop the cancer from coming back. Patients want to be cured of their cancer and don't think about the side effects of treatment. They want to know if the cancer will come back and what they can do to stop it. In Canada, there is only one adjuvant therapy available (pembrolizumab). This needs to be started within 12 weeks of surgery and taken for one year. There can be serious side effects to treatment. The decision aid helps people decide whether they should take adjuvant pembrolizumab. It talks about what will happen, side effects, and the challenges of staying on the drug. The decision aid helps patients make the right decision for them and their families. KCA is willing to share their decision aid with IKCC affiliates. Please email Christine Collins for more information.

Peer navigation

Luciana Holtz, Instituto Oncoguia (BR)

Instituto Oncoguia is a patient advocacy organisation founded 2009. They provide support services, including a patient navigation programme, which started in March 2023. The patient navigation programme provides peer support to help patients through a fragmented treatment pathway. They provide quality information, break down barriers to self-care, help with early diagnosis and treatment, and improve outcomes and quality of life for cancer patients. The programme is running in two hospitals. There is a patient navigation coordinator and four navigators in each hospital. The navigators have been trained and are committed to serving the community. Their day-to-day activities include community resource allocation, educational presentations about self-care, treatment, and diagnosis etc. They must be flexible to meet patient needs and respect the rules of the hospital.

What's new in kidney cancer genetics, genomics and hereditary disease

Moderators: Dr Rachel Giles, IKCC CEO (NL) & Dr Eric Jonasch, IKCC MAB Chair (US)

Clinician perspective

Dr Jose Claudio Casali, Head of Healthcare Services, AC Camargo Cancer Center, São Paulo (BR)

Dr Casali is a geneticist specialising in oncology. His main interest is hereditary kidney cancer diseases, especially von Hippel Lindau (VHL) disease. Hereditary kidney cancer results from changes in the structure of certain genes (mutations) that are passed on in families. People with close family members with kidney cancer need to be

screened for the genes that cause hereditary kidney cancer. If they are found to carry these genes, they need to be followed-up regularly to check for signs of kidney cancer.

The microbes that live in our guts (the microbiome) are important for cancer prevention. People can improve their lifestyles to decrease cancer risk through diet (to improve their microbiome) and exercise to reduce inflammation in the body. Age, lifestyle (obesity and smoking), inflammation (arthritis), and genes all affect why some people in the same family get cancer, while others don't.

Genetic testing of blood or saliva is needed to find hereditary diseases. Genetic testing can be used to determine the risk to other family members as well. Most countries do not have genetic testing guidelines. Patients will also need genetic counselling to help them cope with the disease, and what to expect in the future for them, their children, and other family members. Genetic testing can result in early detection of tumours and better outcomes. It can also change the course of treatment, e.g., patients with hereditary kidney cancer are less likely to have their kidney removed in case they develop more tumours in the future. The surgeon will try to preserve kidney function, otherwise the patient could end up on dialysis.

Mutations in various genes can cause different kidney cancer subtypes, e.g., mutation in the *VHL* and *BAP1* genes cause clear cell kidney cancer, *MET* gene for papillary type 1, *FH* gene for papillary type 2, and *FLCN* gene for chromophobe kidney cancer.

VHL disease causes tumours in the eyes (retina), brain and spinal cord (hemangioblastomas), adrenal gland (pheochromocytoma), kidney, pancreas, testis, and the endocrine system (neuroendocrine tumours). In Brazil, about 100 families and >300 patients have been identified with VHL through genetic screening tests. However, about 5,000 patients have not yet been diagnosed because they do not have access to genetic testing. Because VHL affects young people in their mid-twenties, genetic screening needs to start early. Most patients are not followed-up because they do not have access to specialist doctors. VHL can be avoided in the next generation through in-vitro fertilisation and embryo selection. This is a procedure that is not covered by public insurance and not available to everyone.

Other genetic kidney cancers that can be inherited include Birt-Hogg Dubé syndrome (*FLCN* gene), hereditary leiomyomas and RCC (HLRCC) syndrome (*FH* gene), succinate dehydrogenase RCC (*SDHB*, *SDHC*, *SDHC* genes), angiomyolipoma (*TSC1*, *TSC2* genes), translocation Xp11 and MiT translocation RCC.

In summary, Dr Casali recommended genetic testing for kidney cancer where there is evidence in a family of a hereditary kidney cancer syndrome, but this is not yet possible in many parts of the world.

Patient perspective

Carlos Alberto Fredes, Argentina VHL Group (AR)

VHL disease is a rare genetic condition leading to an increased risk of clear cell kidney cancer. VHL can be very difficult for patients and families. Mr Fredes did not know that he had VHL disease. When he was 40 years old, he was experiencing vision problems and went to seek medical care. Unexpectedly, he was diagnosed with kidney cancer and VHL disease. Both Mr Alberto-Fredes and his brother were diagnosed with clear cell renal carcinoma in the same year and, oddly enough, both later relapsed in the same year. His brother was treated with sunitinib and immunotherapy and has done well, requiring no further treatment. Whereas Mr Fredes is now on his fifth line of treatment. It begs the question why did the treatment work for his brother and not for him? It also demonstrates the need for further genomic research in kidney cancer.

In Argentina it is often necessary to prove you have cancer and seek legal help to obtain treatment. The Argentine government does not want to pay for treatments. Patients, who are already stressed by their diagnosis, need to turn to the courts for justice. The Argentina VHL Group counsels and supports patients. Likewise, genetic testing is

difficult to obtain in Argentina. Currently, it is available only in two private hospitals and is badly needed in the public system.

While the Argentina VHL Group works with all patients, their focus is lower income patients with the greatest need. He thanked Dr Casali and others who have dedicated their lives to the treatment of kidney cancer.

Day 2

Overcoming challenges in developing countries

Moderator: Lauren Pretorius, Campaigning for Cancer (ZA)

Lyat Granati, Max Foundation (CL)

Jyoti Patil Shah, V Care Foundation (IN)

This session started with the Go Green, Think Green World Kidney Cancer Day 2023 campaign video by the [V Care Foundation](#) to raise awareness of kidney cancer in India.

Low-middle income countries represent 3.2 billion people between them (India, South Africa, South America, Asia-Pacific). The barriers to healthcare faced by these countries are similar, and include transport, access to medicines, and financial toxicity. This discussion focused on some of the innovative ways these countries have used to overcome these challenges.

Transportation

The cost of transportation can prevent people going to see their doctor when they first develop cancer symptoms. In South Africa there is a ticketing app that allows patients free public transport. This app is funded by [Campaigning for Cancer](#) in South Africa. For vulnerable patients or those who need a wheelchair can be 'prescribed' individual transportation from rural areas to regional hospitals for treatment.

In India, patient groups organise and fund transportation for patients travelling to regional hospitals.

[The Max Foundation](#) also provides funding for transportation in Africa, Asia Pacific, Latin America, and India.

Access to medicines

Only 30-55% of cancer medicines on the World Health Organisation (WHO) essential list are available in low-middle income countries, and often only if patients are willing to pay for them. There is serious government underfunding and poor supply of medicines.

V-Care in India has arranged access programmes for kidney cancer medicines with pharmaceutical companies. These programmes are for patients with low income who are not able to afford treatment, even when it is prescribed by the doctor. A central government funded agency helps patients get treated in hospitals. Through these schemes, 80-90% of patients are treated free of cost.

The Max Foundation has a programme called Max Access Solutions; a global access programme launched in 2017. The programme is running in 70 countries and provides free medicines to people who are not able to pay for treatment. The medicines are provided by the pharmaceutical companies.

In South Africa, Campaigning for Cancer provide legal assistance to patients for reimbursement of medicines.

Financial toxicity

Financial toxicity is the harmful effect of the high cost of treatment on a person's quality of life. Many people in low-middle income countries rely on social grants and charity to help pay for their cancer treatment. Very poor

people are unable to meet basic needs such as food, accommodation, and transport during their cancer treatment; this greatly impacts the finances of patients and families. Some people need to sell personal belongings to meet healthcare costs. Having cancer is very stressful, and this is made worse by financial toxicity.

Max Access Solutions is a Max Foundation programme, which obtains donated drugs from pharmaceutical companies and distributes them to patients in many countries. They also provide financial and emotional support to patients. In South America, the Max Foundation has agreements with the ministry of health in several countries to provide financial support to patients and find creative solutions to support patients.

In South Africa there is no social protection system to provide a safety net for patients. The government can sue charities for supporting patients, so charities help patients with legal costs.

V-Care India provides financial support to patients in Mumbai. This is used for accommodation, food, and transport when the patient is having treatment. They are extending their support to regional hospitals outside Mumbai and to marginalised communities. There is a government health card scheme that allows families to benefit from free healthcare, but some families still find it difficult to fund treatment and don't get any financial support. This is where V-Care can help.

Early detection

Moderator: Carlos Castro Sanchez, Asociación ALE (MX)

Clinician perspective

Dr Stenio Zequi, Head of Urology, AC Camargo Cancer Center, São Paulo (BR)

The timing of a cancer diagnosis is essential for early and successful treatment of patients. Half of all kidney cancer cases are reported in North America and Europe and the number of cases is increasing. However, the number of people dying from kidney cancer is not changing. This may be because of improved scanning techniques, earlier diagnosis, and better treatments.

The most common signs of kidney cancer are back pain, a lump in the abdomen and blood in the urine. Medical history needs to be evaluated for kidney cancer risk factors. Few cases are detected by physical examination alone, and it is more common for kidney cancer to be diagnosed on a scan. About half of all diagnoses are made when a person has an examination for another condition (incidental diagnosis). Ultrasound scans are low cost and useful for early detection of kidney tumours. Ultrasound can diagnose solid tumours and cysts, but a biopsy may be needed to determine whether the tumour is cancer. Some kidney cysts (Bosniak cysts) may become cancerous; these need to be diagnosed early and appropriate action taken (surgery for cancer, observation for cysts). Modern scanning techniques (CT or MRI) can detect small cancerous tumours in the early stages of the disease when there is the best chance of a cure.

There are about 16 subtypes of kidney cancer, and some are more aggressive than others. Treatment is individualised according to subtype, so it is useful to know the subtype before treatment starts. This requires a biopsy. Patients with symptomatic tumours have less favourable outcomes and reduced survival rate. About 20% of small renal masses are not cancer (benign). Small renal masses may need to be biopsied to determine treatment (surgery or observation). Some kidney cancers are hereditary, and patients may have tumours in both kidneys and multiple tumours. It is useful to know the family history of these patients for early detection of tumours.

Patient group perspective

Liz Leff, National Kidney Foundation (US)

Liz Leff is a kidney cancer survivor, having been diagnosed with stage 1 kidney cancer 9 years ago after an incidental finding on a scan. She had a laparoscopic partial nephrectomy. At the time, she felt lost and did not really

understand her disease and treatment options let alone know where to find and tap into resources for kidney cancer. She sought out the [National Kidney Foundation](#) (NKF) in the United States and since then she has joined the staff and focuses on kidney cancer within the Foundation.

Recognising the kidney cancer patient's need for simple yet accurate information has led the NKF to create a series of six 1–2-minute animated videos, called KidneyClips, about the kidneys, kidney cancer, diagnosis, surgery, immunotherapy, targeted therapy, and precision medicine. The videos can be viewed as a series or stand alone and are available in English and Spanish. The videos are currently being translated into Chinese, French, Italian, Japanese, Korean, Nigerian (Hausa), Polish, and Swedish at the request of patient organisations in these countries. If more information is desired about these videos, please [email Liz Leff](#).

UK Yorkshire Kidney Screening Trial

Professor Grant Stewart, Professor of Surgical Oncology, University of Cambridge, Addenbrookes Hospital (UK) virtual presentation

Surgery is very effective if the cancer is identified at early stage and gives people the best chance of a cure. Current screening programmes target a particular sex or age group, e.g., breast screening for older women and prostate screening for older men. Screening programmes need to target people at high risk of kidney cancer and focus on early cancer detection when the cancer can be treated successfully.

Screening programmes for early diagnosis should be set up if the condition is an important health problem and there is high mortality. Kidney cancer is the 7th most common cancer in the UK and half of all patients will not survive. There is a predicted increase in incidence and mortality over the next 10 years. Screening is possible if there are facilities for the diagnosis of the cancer and treatments are acceptable. There is a recognisable early stage of the cancer, and the natural history of the disease is well understood. There is a suitable test/examination that is acceptable to most of the population, e.g., urine or blood tests for tumour DNA, ultrasound, or CT scans. There should be an agreed policy on who to treat as patients. Cost of screening needs to be balanced against expensive treatments, especially when people are on treatments for a long time.

[The Yorkshire Kidney Screening Trial](#) piggy-backed on the UK lung cancer screening trial which used a CT scan of the chest and abdomen. It screened patients between 50-80 years old with a history of smoking. The researchers were looking at whether this was a useful way of screening for kidney cancer and whether it is acceptable to people and healthcare professionals. They were looking at the number of kidney cancers found, the stage of the cancer, the number and nature of any other cancers found, and other non-cancer findings. More than 4,000 people were scanned and completed the 6-month review. There was a cost effectiveness study, and the results will be published in August 2023.

The trial diagnosed 40 kidney cancer patients. All patients found the screening programme acceptable and felt lucky and grateful to be involved. They were not overly concerned about the harms of being exposed to radiation during the scan. A quarter of kidney cancer cases were found in people who smoke. The screening programme also detected a high number of abdominal aortic aneurysms, which could have ruptured causing death. Other cancers were also detected, and the patients have now gone on to have surgery.

This screening programme is of great interest to the public, clinicians, and policymakers (government). The lung cancer screening programme is being rolled out across the UK, and a randomised trial of an abdominal screening scan is planned later this year.

The Yorkshire Kidney Screening Trail resulted in more work for healthcare professionals because more cancers/conditions were detected. It is important that economic or psychological harm is avoided in people through the detection of non-serious incidental findings. The optimal frequency of the screening programme also needs to be determined, along with the effect of exposure to extra radiation. The lung cancer screening programme is every two years, but the kidney cancer screen could be done every 5-7 years and finish at age 75.

However, screening and follow-up will need to be personalised. Ultrasound is cheaper than CT scans and may be a screening option, but ultrasound is also not as good as CT for detecting cancers. Also, in the UK ultrasounds are not done by radiologists who have the expertise to identify cancers.

One problem with screening programmes is reaching the most deprived population. Telemarketing can be used to persuade these people to come for a scan.

Diagnosis to treatment (supporting patients)

Moderator: Claudia Ungarelli, Associazione Nazionale Tumore del Rene (ANTURE) (IT)

From the moment someone is told they have cancer they can feel overwhelming stress, anxiety, and distress. They fear for their life and the lives of loved ones, and what is going to happen next. The time from diagnosis to treatment can be weeks or months. Patients want to understand the situation, the treatments, and which treatments are accessible. There is a period of self-education while the patient and their family are forced to make sense of a disease that was previously unfamiliar. Patient groups can bridge this information gap.

Clinician perspective

Dr Rachel Giles, Associate Professor, Cancer Center, University Medical Center, Utrecht (NL)

From diagnosis to treatment is a unique period in every patient's life when they confront a unique set of problems. It is a critical time for patients, where they plan their treatment, and they change from living to fighting for their lives. It is a terrifying experience. Patients need to consider their family, work, and social life. Clinicians need to talk to patients about what they are going through during this time. Kidney cancer patients are particularly vulnerable at this time, given that most patients are diagnosed when asymptomatic. Their diagnosis often comes as entirely unexpected.

Most people will look on the internet for information about kidney cancer and why they have it. There is a lot of bad information on the internet, but some good information too. Patients need a certain amount of health literacy to know which is reliable information. Patients who are stressed do not have the right outlook on their disease and do not do as well as patients with a positive attitude. This can be very hard for the clinician to influence.

A cancer diagnosis induces anxiety to such an extent that some patients develop post-traumatic stress disorder (PTSD) that needs treatment (medication, counselling, support groups). Patients should try support groups first and medication last. Anxiety should be recognised by clinicians because once it is treated, the patient will be more in control of their life. Anxiety can be addressed with appropriate counselling, such as mindfulness. Most hospitals offer counselling services, and doctors can help patients access them. Financial toxicity following a diagnosis of kidney cancer can also be a source of anxiety for patients. Cancer can disrupt careers and limit earnings. Doctors can help by directing patients and families to where they can get financial help in these circumstances.

How doctors communicate makes a difference to patients and their relationship with patients. The patients of doctors trained in empathy live longer and have a better experience of diagnosis and treatment. It is important that patients have access to an empathetic or compassionate healthcare professional during the time between diagnosis and treatment. If this is not the case, the patient will have a negative experience of the disease.

Health literacy

Eva Maria Ruiz de Castilla, Esperantra (PE)

Health literacy is the ability to obtain, read, understand, and use healthcare information to make appropriate health decisions and follow instructions for treatment. Health literacy gives people knowledge to access, understand, evaluate, and apply information based on judgement and decision-making regarding healthcare. It helps with disease prevention and health promotion for good quality of life.

Patients are often unable to understand information provided by healthcare professionals when they get a diagnosis of cancer because it is not communicated with empathy. There are three levels of health literacy:

1. Functional health literacy requires people to have basic reading and writing skills needed to understand everyday health information (e.g., reading prescriptions, medicine labels, instructions etc.).
2. Interactive health literacy requires more advanced skills to extract information and understand different forms of communication, and to apply new information to change circumstances (e.g., being involved in discussions about treatment options with healthcare professionals).
3. Critical health literacy is the highest level of skills to critically analyse and use information to allow patients to take control of their health (e.g., identify health risks in the environment and act).

Patient support groups provide information and emotional support. They need to be careful which type of information they provide and the timing of information – too much information can cause anxiety and stress. Patients with a lack of health literacy are more likely to visit the hospital emergency department, be admitted to hospital, and are less likely to take their treatment correctly. This results in higher mortality because the condition is not managed properly.

The World Health Organisation (WHO) considers health literacy as a fundamental aspect of healthcare. Patients should have access to good quality information that they can understand, remember, and use. The WHO has guidelines to produce patient-friendly information. Good information helps patients make good decisions about their healthcare. Well educated patients will navigate the healthcare system better. Patient groups need to produce good, reliable information in patient-friendly language that anyone can understand.

Patient group perspective

Luciana Holtz, Instituto Oncoguia (BR)

There are 700,000+ cases of cancer every year in Brazil. Barriers to diagnosis and treatment are limited screening programmes, lack of access to specialists, limited number of oncology centres, long waiting times for diagnosis and treatment, and lack of multidisciplinary care. This results in personal burden and progression of the cancer.

About 70% of people use the Brazilian public health care services called the Sistema Único de Saúde (SUS). The SUS was established to provide healthcare services for everyone. The SUS is overburdened and needs more funding. People are waiting up to 9 months for a diagnosis and start cancer treatment. Many stakeholders got together to address this, include non-government organisations (NGOs), patients, carers, oncologists, pharmaceutical companies, and politicians. They decided that SUS users should receive their first treatment within 60 days after diagnosis. The 'law of 60 days' was implemented in 2013. In 2019, this was reduced to 30 days for suspicious tumours.

After 10 years, compliance with the law of 60 days has improved over time and has reached 34% of people receiving treatment within 60 days of diagnosis. Nearly half of all kidney cancer patients started treatment after 60 days in 2013. This has reduced to only 1 % in 2023. The SUS needs to monitor treatment delays, clinical outcomes, treatment inequalities, and prioritise cancer care.

Marketplace

Moderator: Margie Hickey, IKCC Board of Directors (US)

Evidence-based advocacy

Dr Rachel Giles, IKCC CEO (NL)

Evidence-based advocacy is using information from reliable sources in a targeted, educated, and professional manner to meet patient needs, e.g., access to a particular medicine. For evidence-based advocacy you need to

back your argument with numbers e.g., 3 in 10 people want access to this medicine. This can be done by asking patients or using surveys. You need to state what you want to happen and why. You need to back up your statements with patient stories, surveys, or letters from families to change people's minds with evidence.

Evidence-based advocacy can influence public policy and educate patients. It is a very important tool for getting your point across to policy makers and doctors. It helps doctors to understand patients. Patient groups can become partners in the care of patients. Evidence-based advocacy can be done through social media, e.g., tagging minister of health into tweets, using WhatsApp groups to work with patients etc. The strongest data comes from the patients in your country. The IKCC global patient survey can be used for evidence-based advocacy. This drives what we do as patient advocacy groups and enables us to collaborate with each other to generate data together.

Patient stories are very powerful for evidence-based advocacy. They can be used to enhance data from patient surveys in policy reports and add emotion to the report. Quantitative data from surveys can be backed up with qualitative data from patient stories. Surveys can be used to confirm anecdotal observations in the community. Evidence-based advocacy can be used for prevention campaigns and to gain access to medication.

Examples: In Poland, quantitative data from hospitals was used to recommend kidney cancer specialist hospitals and to encourage patients to go to the specialist hospitals for treatment rather than their local hospital. In Korea, a survey showed that 95% of patients with stage 1 cancer have stress and anxiety. The Korea Kidney Cancer Association used this to advocate for psychological support for kidney cancer patients from the Korean health service.

Peer support

Christine Collins, Kidney Cancer Canada (CA) & Liz Leff, National Kidney Foundation (US)

Peer support is matching people with similar disease stage, sex, and situation to enable them to provide mutual support. Peer support volunteers are trained to provide patient support. They are not clinically trained and don't give clinical/medical advice for legal reasons. Support is geared to the experience of patients and their needs. Peer support can be therapeutic reducing stress and anxiety.

Newly diagnosed patients often need peer support, but it also benefits people who are further along in treatment. They find relief from talking to people who truly understand what they are going through. Calls are private, confidential and people seeking support are encouraged to share freely; however, it is always their choice what and how much to share.

Patient groups who offer this service often have rigorous screening procedures to make sure only patients/family are on the call. Peer support volunteers are also screened with criteria for selection. These volunteers must be empathetic, be able to hold their own, be a good listener, and interested in helping others. To be a peer support volunteer is not right for everyone; they need the right personality to be able to back away and only offer help when they can. Some patient groups have guidelines for both the person giving help and needing help. These guidelines cover privacy issues and patient choice about sharing information. This helps to avoid litigation. The [National Kidney Foundation](#) has information about how to become a peer mentor on their website. [Kidney Cancer Canada](#) and other patient groups have peer support agreements to create a safe and reliable place to share information.

Health literacy

Eva Maria Ruiz de Castilla, Esperantra (PE/US)

Following up on the presentation earlier in the day, Ms Ruiz de Castilla led a discussion with participants exploring how important health literacy is to patient organisations. Together the group explored best practices for enabling health literacy of the patients and carers they serve. It is important to ensure that health information and services are provided in a manner that meet the needs and interests of patients and carers.

Telling patient stories with purpose

Jilda Lazer, Reverb Consulting Group (CA)

Patient stories can be very powerful for driving change and supporting evidence-based advocacy. Patient groups can use patient stories to educate other patients, support people by sharing experiences, and build connections so people don't feel alone. Patient stories can be used in evidence-based advocacy to demonstrate what is wrong with healthcare and what needs to be changed.

Tips for patient stories:

- Know your audience, e.g., other patients/carers, public, healthcare professionals, government/policy makers. This determines what you say and the level of information. Time is often limited, and the audience might have limited knowledge of the condition.
- Build your message. What is the main thing you want your audience to know from your story. Don't be afraid to say it more than once. Support key message with facts and emotion. Use a specific call to action.
- Build connection using images. Search for things you have in common to build a connection with others to make them care about the issue you are presenting. Humanise the issue to add credibility and inspire others.
- The story does not have to be linear i.e., start at the beginning and go to the end, and you don't have to include everything. Adapt the story to the purpose for each audience.
- Sharing negative stories. Try to guide the patient through their story so they can present it in a positive or productive way, e.g., by talking about how a person overcame their problems.

The Cecile and Ken Youner IKCC Scholarship

Moderator: Dr Eric Jonasch, Professor of Medicine, MD Anderson Cancer Center, Houston, Texas and IKCC MAB Chair (US)

Dr Jonasch announced the winners of the Cecile and Ken Youner IKCC scholarship for 2023. This scholarship was established in 2018 to honour the IKCC emeritus board member, Dr Ken Youner, a kidney cancer patient who contributed to the establishment of the IKCC. Cecile Youner also had breast cancer, and together they lobbied for better cancer treatments. Dr Youner, a gastroenterologist, was a passionate patient advocate, and teacher and friend to many in the community. This scholarship allows a trainee to attend the IKCC Global Kidney Cancer Summit to present their work and recognises emerging talent in the kidney cancer world. It enables the individual to see patient engagement in action and to support this going forward. This is the sixth time the scholarship has been awarded and this year there are two recipients, Dr Yuly A Remolina Bonilla, a urological research fellow from the National Autonomous University of Mexico, Mexico City and Amanda Ikegami, a PhD student from AC Camargo Cancer Centre, São Paulo, Brazil.

The existing healthcare system inequities in Mexico and its impact on survival outcomes in Mexican patients with metastatic renal cell carcinoma

Dr Yuly A Remolina Bonilla, National Autonomous University of Mexico, Mexico City (MX):

Dr Bonilla examined the existing health inequalities in Mexico and their impact on survival outcomes in patients with metastatic kidney cancer. Survival of metastatic kidney cancer patients is determined by access to anti-cancer medication and the number of medications they have.

In Mexico, access to treatments is restricted, and only patients with private health insurance have access to the latest treatments. Of the 924 patients in the study, more than half had no health insurance, and most had to travel into the city. Only 2% had private health insurance. Most patients without insurance are diagnosed with higher risk

cancers, with poor prognoses. Of the patients without insurance, only a third received treatment, mostly sunitinib. Overall, only 64% of patients received a first line treatment and most of these patients did not receive a second or third line of treatment.

Those patients without health insurance had shorter survival (13 months) compared to 98 months for those with state health insurance and 147 months for private patients. They were also 1.5 times more likely to die than the other patients. Survival is, therefore, highly influenced by the healthcare system they belong to.

The involvement of neutrophils - cells of the immune system - in the progression of renal cell carcinoma

Amanda Ikegami, AC Camargo Cancer Centre, São Paulo (BR):

Ms. Ikegami's research looks at the mechanism of kidney tumour thrombus, or tumour blood clot formation and the involvement of neutrophils (cells of the immune system) in kidney cancer. A tumour blood clot forms from the tumour and can grow into the large veins next to the kidney in 4-10% of cases. However, how these tumour blood clots form is not well understood. Tumour samples from patient's kidney cancers (grafts) were placed into mice to better understand this process. These grafts grew the same tumours in the mice as in humans. The ratio of neutrophils to lymphocytes (another immune cell) gives an indication of survival and were also assessed.

Neutrophils can both kill tumour cells and help them grow. Tumour cells cause the formation of neutrophil extracellular traps or NETs, which cause tumour blood clots to form. A substance called interleukin 8 (IL-8) attracts neutrophils to form NETs. Levels of IL-8 were higher in mice with tumour blood clots in their veins. Kidney cancer secretes IL-8 that attracts neutrophils causing the formation of NETs and tumour blood clots. A drug that stops NET formation could be a potential treatment to stop tumour blood clots. IL 8 could be a predictive biomarker for the formation of tumour blood clots. This needs to be looked at in kidney cancer patients.

New developments in localised disease

Moderator: Berit Eberhardt, Uronauten (DE)

Clinician perspective

Dr Stenio Zequi, Head of Urology, AC Camargo Cancer Center, São Paulo (BR) & Dr Michael Jewett, Professor of Surgery (Urology), Princess Margaret Cancer Centre and the University of Toronto (CA)

It is important to know the stage of the cancer because this will drive treatment decision-making. Localised kidney cancer includes stage T1 tumours (less than 4cm), T2 tumours (between 4 and 7 cm) and T3 tumours that have grown into the veins or surrounding fat. About two thirds of localised tumours are discovered when a patient has a scan for another condition. This is not the case in low-middle income countries where there are fewer scans.

Nearly three quarters of patients with localised kidney cancer survive for 5 years or more after surgery and are likely to be cured. The signs and symptoms of kidney cancer are often vague, and ultrasound, CT, or MRI scans are used to diagnose kidney cancer. Ultrasound is relatively cheap, but it needs to be done by a radiologist. In some countries, ultrasound scans are done by a clinician who is not experienced at looking for tumours, e.g., the family doctor or emergency room doctor. Ultrasound is also limited by the size and shape of the patient. Not all tumours are cancerous (malignant); CT or MRI are better at diagnosing kidney cancer.

Most kidney cancer is discovered as a small renal mass. These are often found in older people with other medical conditions (comorbidities). Most (about 80%) are clear cell renal cell carcinomas (RCC). About 20% are non-clear cell subtypes, such as papillary RCC or chromophobe RCC. Only a biopsy can diagnose the subtype of kidney cancer. Biopsies can be taken through the skin (percutaneous) with a needle guided by a scan. This is an outpatient procedure using local anaesthetic. However, the use of biopsy is dependent upon local guidelines. The tumour can

also be biopsied after it has been surgically removed. The subtype of cancer can then be confirmed by looking at cells from the tumour using a microscope.

It is important to determine the subtype of kidney cancer because the treatments are different. Benign renal masses are rarely removed with surgery. A PET-CT scan using a weakly radioactive form of an antibody called ^{89}Zr -DFO-girentuximab can be used to help tell the difference between clear cell RCC, normal tissue, and other tumours. Girentuximab attaches to an enzyme called carbonic anhydrase IX (CAIX). This enzyme is found in clear cell RCC tumours and the ^{89}Zr -DFO-girentuximab shows up red on a PET-CT scan. The accuracy of this technique is 85-87%.

Some localised kidney cancer (about 40%) is very slow growing and can be managed with active surveillance. The gold standard for the treatment of localised kidney cancer is radical or partial nephrectomy. Partial nephrectomy is for small tumours (stages 1 and 2) or people with one kidney or reduced kidney function. Nephrectomy can be done laparoscopically and using a robot, dependent on the stage, size, location of the tumour and nearby structures. Patient characteristics also need to be considered, e.g., previous surgery, lifestyle, symptoms, weight, performance status, socioeconomic factors, and the patient's preferences. Patient survival for both partial and radical nephrectomy is identical. However, partial nephrectomy protects kidney function and is better for the patient. The use of partial nephrectomy is increasing. 3D printing can be used to help visualise the kidney and the tumour to help the patient understand surgery. This leads to better shared decision-making.

Tumour enucleation (removal of the tumour so that it comes out whole) is useful for very small tumours and for patients with multiple tumours and other conditions. Localised kidney cancer can also be treated using ablation, e.g., radiofrequency ablation, cryotherapy, high intensity focused ultrasound (HIFU), or microwave ablation.

Some countries use adjuvant therapy after surgery to prevent the cancer from coming back. Most adjuvant clinical trials have been negative. However, sunitinib and pembrolizumab have been approved as adjuvant therapies for high-risk localised kidney cancer in some countries. When deciding whether to have adjuvant therapy, patients and clinicians need to consider the side effects, financial toxicity, and over-treatment (60% of high-risk patients will never progress, regardless of adjuvant therapy). We need better patient selection for adjuvant therapy.

Patient perspective

Christine Collins, Kidney Cancer Canada (CA) & Liz Leff, National Kidney Foundation (US)

Canadians Andrew Weller and Christine Collins have localised kidney cancer and have been on long term active surveillance for slow growing cancer for several years. This is preferable to having invasive surgery to remove their cancer; however, there is always the worry that the cancer might start growing and treatment would be needed. Patients on active surveillance are matched with other patients on active surveillance to enable them to share experiences and reduce anxiety.

KCCure in the USA has a database of patients on active surveillance. The Children's Oncology Group and the NHS both hold a database of children on active surveillance. It might be useful to use these databases to gather genetic information about people on active surveillance to look for genetic biomarkers for the risk of disease progression.

People with benign renal masses are followed-up much less frequently than people with malignant renal masses. Many countries have guidelines for the frequency and nature of follow up after surgery for localised kidney cancer and small renal masses.

Day 3

Encouraging volunteers

Moderator: Bryan Lewis, KidneyCAN (US)

KidneyCAN

Bryan Lewis, KidneyCAN (US)

KidneyCAN is a patient advocacy group in the United States whose mission is to accelerate cures for kidney cancer. They engage in patient advocacy and research by supporting government and industry research, facilitating research collaborations, and offering financial support for clinical and laboratory researchers with promising ideas. They do a lot of their work through encouraging volunteers. Bryan Lewis started KidneyCAN with Ralph Knapp. Kidney CAN was formed by and for patients to address unmet needs for both patients and researchers. Sadly, Ralph died last year. KidneyCAN has a team of volunteers that stretch across 30 of the US states.

KidneyCAN raises awareness of the unmet needs for kidney cancer patients and use advocacy to carry their message to Washington DC for research funding to find a cure for kidney cancer. Volunteers fuel their mission - only the president, operations manager and communications manager are paid. All others are volunteers. They gather their community of volunteers through education and empowerment, building a community and engaging through social media.

Their patient resource centre is used to educate and empower volunteers by giving them the tools to speak about kidney cancer. There are 4 main areas; understanding your kidney cancer diagnosis, treatment options, how to connect and find support groups, and managing your ongoing care and treatment. Patient stories are also very powerful, especially for policy work. The patient voice is at the front and centre of what they do.

Throughout the year, volunteer advocates, including patients, carers, researchers, and clinicians engage with their elected representatives in order to increase government funding for kidney cancer, and in particular funding for the National Institutes of Health (NIH). Volunteers do not need experience for this. They are given a toolkit to help them get their point across, tell their story and advocate for more research funding. It is important to note that the funds raised may be available to kidney cancer researchers from the US and internationally.

Judy Nicholson Kidney Cancer Foundation

Linda Ostoski, Judy Nicholson Kidney Cancer Foundation (US)

The Judy Nicholson Kidney Cancer Foundation provides support and education to kidney cancer patients and their caregivers. They provide educational "Celebration of Hope" symposia, live in-person seminars throughout the US. and webinars. Their virtual online webinars are available globally. They also run advocacy days for patients and carers with healthcare professionals to raise awareness. The organisation started 12 years ago and is run mostly by volunteers, with a few paid staff. Most volunteers are kidney cancer patients and advocates.

They started out by fundraising for a couple of years. They then started running in-person symposia and branched out using Zoom and now they hold monthly kidney cancer conversations with patients. Sometimes they have healthcare specialists attend the kidney cancer conversations, or they have patient stories. These are recorded and placed on their website. They have a volunteer who advocates with legislation members in Washington, DC. They empower patients to become advocates.

They have a volunteer patient and carer advisory council. Volunteers are often identified at the live symposia. These are attendees who find the symposia valuable and want to give back, so they join the charity as advocates. To recruit volunteers, you need to build relationships with people who are all on the same mission and want to share their stories/experiences. This requires trust, relationship building, having the same goals and a passion for

the cause. It is also important to let volunteers use their strengths in the organisation and have ownership of what they do.

Metastatic disease (advanced disease)

Moderator: Radha Chitale, Senior Director of Communications, Kidney Cancer Association (US)

Clinician perspective

Dr Matías Chacón, Head of the Department of Oncology, Instituto Alexander Fleming, Buenos Aires. (AR)

Globally, kidney cancer is the 16th most common cancer. There are large numbers of cases in Latin America, and the cases are increasing. However, the number of people dying from kidney cancer is not changing. Kidney cancer is the 5th most common cancer in Latin America and there are 14 new cases diagnosed each day. Brazil, Argentina, Mexico, and Columbia have the highest numbers of kidney cancer patients. Argentina has 5,000 cases/year and nearly 2,500 deaths/year from kidney cancer.

There needs to be a multidisciplinary approach for treating metastatic kidney cancer with precision treatment. Also, expert pathology is important for the diagnosis of rare RCC subtypes that need different treatments. Because kidney cancer develops a rich blood supply, targeted therapies that stop the growth of new blood vessels (angiogenesis), such as vascular endothelial growth factor receptor (VEGFR) inhibitors and mTOR inhibitors are useful for treating metastatic kidney cancer. Also, immune cells such as T cells accumulate in the kidneys. These T cells can be activated to kill cancer cells by immunotherapies. Combinations of immunotherapy and VEGFR inhibitors as a first treatment after surgery can result in a 70% response to treatment. Treatment options (surgery, active surveillance, anti-cancer medication) need to be discussed and decided with the patient and family.

The main aim of treatment is to cure the cancer. Other aims are to improve symptoms and control the disease over time. These treatments can have severe side effects that need to be managed. Also, patients need to be given the right treatment at the right time and the science of how drugs work needs to be considered.

Most drugs are available in Argentina, but the healthcare system is very fragmented with private and public patients. The drugs are often too expensive for state hospitals, and only nivolumab, sunitinib and pazopanib are available on the state. It is the same situation for all Latin American countries. It is difficult to afford the right drug at the right time and demand exceeds financial resources.

Barriers to access to medicines are access to healthcare, education of treatment guidelines, no multidisciplinary teams, and lack of clinical trials. However, there have been advances in the care and treatment of kidney cancer patients; VICARE tries to improve access to medicines. There are improvements in surgical techniques, and improvement in the medicines to treat metastatic disease.

Clinician perspective

Dr Diego Abreu, Urologist, Pasteur Hospital, Montevideo (UY)

Worldwide there are 431,000 cases of kidney cancer diagnosed each year. Nearly half of these people will die from their disease. In the USA 82,000 cases are diagnosed each year and only 20% will die. The number of cases is lower in developing countries, probably due to under diagnosis. The death rate has decreased since the 1990s likely due to earlier diagnosis and improvements in surgery and treatments. Worldwide survival continues to improve, and 5-year survival is just over 80%.

For locally advanced kidney cancer there is a 20-40% recurrence rate, of which nearly half are metastatic disease. Follow-up after surgery is essential for these patients, and the length of follow-up should be decided together with the patient. Dr Abreu recommends no less than 10 years of follow-up. If metastases are found early, this may

extend life. The average survival time for metastatic disease is 19 months with nearly half of patients alive at 12 months. The amount of cancer (tumour burden) and the subtype of kidney cancer are important factors impacting survival. If metastases are found in more than 2 places in the body, survival drops to 34% at 12 months and 7% at 12 months if there are more than 10 metastatic sites. Metastases in the pancreas or thyroid gland have a lower survival rate.

In Latin America if metastases are found at the time of diagnosis, most patients (95%) only have surgery followed by palliative care. Only a small number of patients have anti-cancer medication. Of these, most will only receive first-line treatment with only 7% receiving a second line treatment. The anti-cancer medications available are sunitinib, pazopanib and nivolumab. 4% of patients have a complete response to treatment, while 20% have a partial response. Treatment is stopped in most patients because the cancer is getting worse (progressing) or in a smaller percentage of patients (8%) because of side effects.

There is large diversity in healthcare systems within Latin America. State-funded healthcare depends on the resources available in each country and the ministry of public health. In Uruguay, everyone has public health care funded through taxation. Patients can access combination treatments but need to go through a legal process to get access. For public patients, this process takes 3 months, for private patients it usually takes about 2 weeks. However, nearly all patients are approved for treatment with pembrolizumab plus axitinib as a first medication.

Clinician perspective

Dr Eric Jonasch, Professor of Medicine, MD Anderson Cancer Center, Houston, Texas and IKCC MAB Chair (US)

Brain metastases are found in 10% of patients with metastatic kidney cancer and are associated with shorter survival times (average 16.5 months). The treatment of kidney cancer brain metastases needs a multidisciplinary approach. The best way to treat kidney cancer brain metastases remains unclear. The IKCC commissioned a report into the management of brain metastases in patients with kidney cancer. To improve patient care and standardise treatment, experts from different specialities were asked about their challenges and unmet patient needs. The report presents suggestions for screening and diagnosis, management of single and multiple brain metastases, medication, and surgery.

Patients with localised or metastatic kidney cancer will have a brain scan only if they have brain symptoms (about 58% of patients). Additional scans are needed if they develop brain symptoms. If brain metastases are discovered, 80% of patients are recommended brain scans every 2-4 months.

Single brain metastases are treated with stereotactic radiosurgery (SRS) or surgery. SRS focusses many beams of radiation onto the metastasis to destroy it. Multiple brain metastases (from 2-10 metastases) are treated with whole brain radiotherapy. This can cause problems with brain function, and SRS is better, if possible. The IKCC report suggested that surgery and SRS are the main treatments for brain metastases. It also suggested that a multidisciplinary team and the patient or family are involved in shared decision-making for the treatment of brain metastases.

Because patients with brain metastases are excluded from clinical trials for new medicines, there is not a lot of data for the treatment of brain metastases with anti-cancer medication. Lenvatinib and cabozantinib can shrink brain metastases, and combinations of immunotherapy and targeted therapy can slow the growth of brain metastases. Immunotherapies can shrink brain metastases, but the effect is small. The combination of pembrolizumab plus lenvatinib is being looked at to see if it can shrink brain metastases without radiation.

Patient perspective

Jin Young Paik, Korea Kidney Cancer Association (KR)

A diagnosis of metastatic kidney cancer is life-transforming for the patient and their family. There are social and psychological issues associated with diagnosis and treatment. When a patient develops metastatic kidney cancer,

they blame themselves and can become depressed. The treatment can be overwhelming. There are significant challenges depending on how the cancer has spread. The patient will meet with many specialities. This involves time and cost. There are also challenges when changing treatment and missed treatment opportunities. In Korea, there are strict regulations for medicines and insurance cover. There is a heavy financial burden for treatments that are not covered by health insurance.

Health insurance will cover the cost of the first treatment for patients with low-risk disease (sunitinib and pazopanib) but not the second treatment. For patients with high-risk disease, insurance will cover the costs for immunotherapy, but not for combination treatments. This is a financial burden for patients and their families. The Korea Kidney Cancer Association plays a vital role in educating, counselling, supporting, and collaborating with patients to give them treatment options. They also make them aware of suitable clinical trials. They empower patients to help them overcome treatment challenges, maintain quality of life while living with cancer, make personal plans and reintegrate them into daily life.

Overcoming challenges in living with and beyond kidney cancer

Moderator: Berit Eberhardt, Uronauten (DE)

Quality of life

Dr Juan Dapuelo, Psychiatrist, Universidad de la República, Montevideo (UY)

Patient reported outcomes (PROs) are reports directly from the person about how they are feeling or performing. Survival data can be improved by including reports from patients on how the treatment affects their bodies, their feelings, emotions, pain etc. These effects are only known to the patient. PROs can help with therapeutic plans and health policies and improve communication with healthcare professionals. Well-designed assessments involving patients are more reliable than general observations.

Health-related quality of life (HRQoL) surveys are PROs. HRQoL surveys are complex questionnaires commonly used to look at the effect of a person's health on their quality of life. They can be used to assess symptoms of disease by ranking them on a scale of 0-10, no symptoms to worse possible symptoms. They can measure some aspects of the quality of a patient's life, such as duration of life, level of activity, perceptions, and social life that are influenced by cancer or treatment. They can be used in clinical trials to look at health related QoL benefits. These tend to look at cancer symptoms, emotional wellbeing, treatment side effects, level of activity, and overall wellbeing. They use a visual analogue scale where the patient ranks their health from 0-100, worst to best health.

The questionnaires used to measure QoL lack information about psychological and financial distress. A better questionnaire including emotional wellbeing, financial toxicity and psychological distress is needed. Patients or patient advocates are needed to help develop these questionnaires and contribute to the design of clinical trials to address real world situations. Patients and patient advocates should be trained and involved in the methodology of HRQoL. Better questionnaires are needed to capture what really matters to patients. HRQoL measurements need to be presented to patients in a way that is understood to help with decision-making.

Kidney health after a nephrectomy

Dr Javier Arteaga, Nephrologist, Private University Hospital of Córdoba (AR)

Patients need to look after their remaining kidney after surgery to prevent chronic kidney disease. Chronic kidney disease is assessed by measuring glomerular filtration rate (GFR) and the amount of creatinine and albumin in the urine. High blood pressure and diabetes can cause chronic kidney disease. Angiotensin-converting enzyme (ACE) inhibitors can be used to prevent or treat chronic kidney disease. Normal GFR (stage 1) is more than 90 mL/min, mild kidney disease (stage 2) is a GFR of 60-89 mL/min and moderate kidney disease (stage 3) is 30-59 mL/min. Less than 30mL/min is severe or end stage kidney disease.

A longer follow-up is needed to determine whether chronic kidney disease after surgery is significant. Partial nephrectomy leaves more kidney function, but radical nephrectomy is better at removing all the cancer. There is a balance between removing the cancer and keeping kidney function in terms of quality and length of life. For large tumours, radical nephrectomy is best, but is associated with a decline in kidney function.

We need to know the patient's kidney function before nephrectomy. Other conditions, such as high blood pressure and diabetes, can cause a drop in kidney function before nephrectomy. These need to be considered before surgery. Patients who have stages 1-3 kidney disease have a larger drop in kidney function over the first year following nephrectomy, than patients with stages 4 and 5. For all patients, it is important to decide between partial and radical nephrectomy, except for patients already with end-stage kidney disease (stage 5).

To protect your kidneys, you need to be aware of the medications that can affect kidney function and manage the drugs that can alter creatinine clearance. What is good for your heart is usually good for your kidneys, e.g., ACE inhibitors to keep blood pressure low, controlling glucose levels (with SGLT inhibitors), and lowering cholesterol. Big data and artificial intelligence will help us predict acute kidney failure and which surgery is best for the patient.

In summary, there is a trend towards partial nephrectomy for small tumours to keep kidney function. Kidney function needs to be measured before nephrectomy and surgery needs to be carried out at specialist centres. Kidney function also needs to be measured after surgery and the patient followed-up. Take the advice of your nephrologist for better kidney health and survival. There are no special diets for kidney health after a nephrectomy. Patients are advised to eat a healthy, well-balanced diet and good nutrition after surgery.

Patient perspective

Andrew Weller, Kidney Cancer Canada (CA)

Survivorship focuses on the health and wellbeing of a person with cancer from diagnosis to end of life; the physical, mental, emotional, social, and financial aspects of cancer that continue through treatment, and beyond. Key factors are the quality of care, patient information needs, and education to make the right decisions with doctors. Factors affecting survivorship are the stage of cancer, support network, medical team, financial factors, age, mental health, attitude, physical condition, patient engagement with treatment plan, and geographic region (urban versus rural).

Sources of information are healthcare professionals (67%), patient groups/charities/websites/blogs/support groups (55%), and the family doctor (50%). However, healthcare professionals have limited time to engage with patients and family doctors do not always have accurate information. Information leaflets about psychosocial support and treatment costs/financial burden from patient groups are useful.

Barriers to successful treatment affect survivorship. These include access to a healthcare professional, access to treatments and side effects. Financial concerns impact the patient and family, and some treatments might not be available due to high costs. The ability to work and loss of income is a financial concern for patients and families. Patients need to consider length of life versus quality of life.

The effects of the cancer can also affect survivorship. These include physical effects, psychosocial effects, spiritual effects, loss of income, limitations on work performance, changes in roles and adjusting to new norms, other diseases/conditions, fear of recurrence and living with uncertainty, and fear of death.

A survivorship plan is needed, including:

- Surveillance for recurrence and screening for other primary cancers
- Monitoring and treating long term and late side effects of treatment (follow-up)
- Health promotion – weight management, physical activity, diet, smoking cessation, reduced alcohol
- Promotion of psychological wellbeing – depression and anxiety, post-traumatic stress disorder, fear of recurrence, return to work, financial issues, body image, sexuality.

The principles of survivorship should include care pathways, treatment summaries and care plans, information and education, and rapid access to the healthcare system if the patient has a recurrence. Carers also need to be

included in the survivorship plan because they need support too. Survivorship is individual and personal and needs to be continuously addressed. We need to lobby for survivorship to be included in the care and treatment plan, long term follow-up of patients for more than 10 years, and the development of a survivorship/follow-up package.

End of Conference Remarks

Dr Michael Jewett, IKCC Chair (CA), Dr Rachel Giles, IKCC CEO (NL)

This was an informative and exciting meeting, bringing together patient organisations from around the world to share best practices, exchange experiences and work together to help improve the lives of kidney cancer patients wherever they live.

All the affiliates were thanked for attending and actively participating in the meeting. The quality and topics of the meeting reflect the input from the affiliates, and all were reminded to complete their evaluations. Appreciation for hard work was given to the audio-visual team, the conference organising committee, and Julia Black and Annika Marshall for managing the meeting logistics.

Written by Sharon Deveson Kell BSc (Hons), PhD, MBA