



# Global Kidney Cancer Summit

13<sup>th</sup> – 15<sup>th</sup> October 2022  
Milan, Italy

## DAY 1

### Welcome to the 2022 Global Kidney Cancer Summit

*Dr Rachel Giles (NL)*

Dr Giles, Chair of the IKCC Board, welcomed everyone to the 12<sup>th</sup> IKCC Conference. The main goals of the conference were to support patient advocates in developing new knowledge and skills about diagnosis and treatment, identify common needs, problems, and challenges in kidney cancer, and share ideas, best practices, and solutions to enhance the work of kidney cancer patient advocates.

Dr Giles welcomed one of our newer affiliates who are hosting this year's summit; the Italian organisation ANTURE (Associazione Nazionale Tumore Del Rene), which is the first kidney cancer patient organisation in Italy.

### Patient group meet and greet

*Moderators: Christine Collins (CA) and Liz Leff (US)*

Each affiliate organisation (29 affiliates) and pharmaceutical company (5 companies) introduced themselves. They explained how they wanted to learn from each other, including best practices, new treatments, and how they can better represent the patient voice globally. Pharmaceutical companies wished to learn how to better support patients and meet their unmet needs.

### Evolution of patient groups - Part 1

*Moderator: Dr Michael Jewett*

#### Patient perspective, Claudia Ungarelli (IT)

Claudia Ungarelli introduced the Italian Kidney Cancer Association, ANTURE. In 2010 two Facebook groups were formed and in 2020 ANTURE was born. Common experiences of patients and families were shared on Facebook, and ANTURE gave practical tips, up-to-date information, and treatment advice. They became patient advocates; they run educational programmes, conduct scientific research, and produce a kidney cancer booklet. They take part in World Kidney Cancer Day, hold webinars and video interviews with patients, carry out public affairs activities, and have established a scientific committee. In the future they are calling for the Italian government to reimburse genomic tests and an online register of these tests for personalised medicine.

#### Clinical perspective, Dr Michael Jewett (CA)

Dr Jewett is a urologist from the Princess Margaret Cancer Centre in Toronto. He talked about encouraging patients and supporting initiatives to advocate for kidney cancer patients and their families, especially those with rare kidney cancer subtypes. Patient engagement in their treatment and care has been demonstrated to be beneficial in many studies. Dr Jewett recently presented the 1<sup>st</sup> IKCC lecture to the European Association of Urology (EAU) concluding that patient engagement is a 'blockbuster treatment' for cancer. The key question for the IKCC is whether engaging patients produces better survival outcomes. In one recent study, access to nurse specialists, educational programmes for management of side effects, timely reporting of side effects, and symptom monitoring all improved overall survival.

### **Starting a patient group, Francisco Rodrigues (PT)**

Francisco Rodrigues from [AC RIM](#) (Associação de Cancro do Rim de Portugal) gave an update on his work to start a patient group in Portugal in 2019. He wrote a personal blog about his disease, where he met other patients and urologists. He listed the things that need to be done to start a patient group, such as agree the name, legal requirements, codes of conduct, and awareness to attract new members. He suggested using social media, such as LinkedIn for doctors, Twitter for everyone, Instagram, Facebook and WhatsApp for patients and the families. The patient group also has a website that is clear, patient friendly and regularly updated. AC RIM run patient meetings, distribute leaflets, place magazines in doctors' waiting rooms, and have a helpline.

### **Overall perspective: Dr Alessandro Antonelli (IT)**

Dr Antonelli, Professor of Urology in Verona advocates for patients to be educated about all aspects of kidney cancer. This is not easy in Italy. In his opinion, patients prefer not to think about their diagnosis. Patients who get over the disease don't want to get involved with advocacy groups. Some patient advocacy groups arise from bad experiences with doctors. Good doctors are the right partners for patient groups and can give advice from a clinical perspective. Treatment for different stages and types of kidney cancer can be very different and not all patients have knowledge of available treatments. There is a need to build awareness through patient groups. He concluded with provocative observations about patient groups advocating for treatments.

### **Kidney cancer hot topics 2022 - Part 1**

*Moderator: Maxine Tran (UK)*

#### **Oligometastatic disease, Miss Maxine GB Tran (UK)**

Miss Tran is a urologist at the Royal Free Hospital in London, UK. They have more than 1800 referrals for suspected kidney cancer each year and perform more than 400 nephrectomies/partial nephrectomies and 150 ablations. They are also a referral centre for rare inherited kidney cancer subtypes. 'Oligometastatic' means 5 or less metastases that spread slowly. A few areas of spread can be treated locally with ablation (cryoablation, radiofrequency ablation, microwave), radiotherapy, surgery, or medication. Treatment is tailored to each patient.

Stereotactic ablative radiotherapy (SABR) uses high doses of radiotherapy directed at the metastasis. In a large analysis of 28 studies including 1602 patients, around 90% of metastases were treated successfully. Treating one metastasis with SABR can influence metastases in other parts of the body. This is due to the immune boosting effect of SABR. Clinical trials are ongoing to look at the effect of SABR with immunotherapy.

Irreversible electroporation (IRE) is a non-thermal treatment using high voltage electricity to punch very small holes into the cancer cell walls leading to cell death. Histotripsy uses high frequency ultrasound to cause tiny bubbles that explode in the tumour cells to kill them. Trials are ongoing with these techniques. Clinical guidelines recommend nephrectomy followed by ablation for small numbers of metastases.

#### **Kidney cancer and COVID-19, Dr Rachel Giles (NL)**

Dr Giles summarised a global patient organisation survey on the effects of COVID-19 on cancer patients. 155 organisations were included. Overall, there was an increase of 44% in support calls and a reduction of 45% in income. In India, 75% of cancer screening was interrupted. For von Hippel-Lindau patients, 44% had their care interrupted. For kidney cancer patients at high risk of COVID-19, only 18% wanted to delay their scans, although 70% had anxiety. Kidney cancer patients were not at greater risk from catching COVID-19, but cancer survivors have high risk of severe COVID-19 if they catch it. For healthcare professionals, 30% had depression and 40% had burnout. Acute kidney injury occurred in 34% of patients with COVID-19 and small renal masses were found in the lungs of some patients, increasing the future risk of kidney cancer. Telemedicine, Zoom meetings, webinars, and YouTube changed the way we interacted during the pandemic.

## Evolution of patient groups - Part 2

### Results from the Affiliate Survey on Communications: Margaret Hickey (US)

*Moderators: Christine Collins (CA) and Liz Leff (US)*

Margaret Hickey, IKCC Board member, reported on the survey about communication between affiliates, with stakeholders, healthcare professionals and the public. The aim was to optimise communication among the kidney cancer community at large. She mentioned websites, newsletters, board meeting reports, conference highlights, report findings, meeting updates and social media. The survey was carried out in June 2022 and there were 18 responses. For content, overall satisfaction was high and the majority said the frequency was just right. Some said the materials were difficult to understand, especially the conference highlights. A lay summary at the beginning would help. Some mentioned that the information was too focused on other parts of the world. Some of the affiliates requested support with translations and/or interpretation.

Most affiliates shared World Kidney Cancer Day information, the Global Patient Survey results, and education and support tools. They were less likely to share policy information and studies from other affiliates. There was a desire to connect more than once a year virtually (13/18 respondents), taking advantage of time zones, and having topical meetings to share best practice and learn from each other. Infographics and videos are a good way to communicate information. Priorities for patient organisations are patient support and education (94%), disease awareness (83%), living well with kidney cancer (78%), access to treatment and diagnosis (72%), quality of life (72%), public awareness (67%) and access to support services (67%).

## DAY 2

### Breakfast session: Misinformation and disinformation, Dena Battle (US)

*Moderator: Margie Hickey (US)*

Dena Battle from KCCure in the US opened by defining disinformation as intentionally false and misleading information, and misinformation as false information. We currently have an overload of information from technology. About a third of this is misleading or inaccurate, but we are 20% more likely to share disinformation. This can lead to confusion, reduce quality of care, and cause financial toxicity. Patients struggle with uncertainty, and this causes desperation to believe mis- and disinformation. Deciding what is mis- or disinformation is subjective and there is little evidence that exposure changes the way patients behave. We need to know the source of the information – is it reputable? And the intent of the person spreading it. A concern was raised that pharmaceutical press releases can be seen as disinformation. These press releases are required by law and caution needs to be taken as they may be written in way that may overemphasise benefit.

To combat mis- and disinformation there are several good practices including:

1. Work together to educate patients about mis- and disinformation
2. If mis- or disinformation is shared on organisation websites, do not share it, or raise attention to it with commentary. Remove it from social media, if possible
3. If you see mis- or disinformation elsewhere, highlight the accurate content and ask for corrections.

## Understanding a diagnosis and communicating it to a patient

*Moderator: Deb Maskens*

The IKCC believes in shared decision-making based upon evidence-driven information. In the IKCC Global Patient Survey in 2020, patients reported a lack of basic knowledge about their diagnosis: Likelihood of survival (42%), subtype of kidney cancer (34%), stage of cancer (18%), risk of the cancer coming back (31%), and treatment options (12%). Urologists often share information verbally when the patient is in crisis and does not take it in. Many patients say their doctor makes the decisions about treatment, but patients want to be involved. About a third are involved to some extent. There is an overwhelming need for psychosocial support across all stages of disease. Patients with localised disease (stages 1-3) are changed by their diagnosis: They continue to refer to

themselves as patients (47%) or sick (27%). While patients can be overwhelmed with too much information, only about 5% of patients are too shocked to understand what is being said to them.

#### **Clinical perspective: Dr Alessandra Volpe (IT)**

Dr Volpe, a urologist from Novara, Italy, gave a clinical perspective on communicating a kidney cancer diagnosis. Sharing bad news is challenging. Patients react differently with fear, grief, anger, and denial. The goal is to support the patient, but doctors often have too little time. Face-to-face meetings are mandatory. Family members should be present, as well as a clinic nurse, if possible. The location needs to be appropriate with enough time.

The approach needs to be friendly, with eye contact, and the doctor needs to anticipate and explore the needs of the patient and family. In the case of multiple consultations, the message needs to be consistent. Use simple language tailored to the patient and do not use jargon. Do not overload the patient with information. Drawings and visual aids are often useful. Check understanding and clarify uncertainties with the nurse later. Show empathy and give bad news clearly. Pause to allow the patient to absorb the information. Be realistic but preserve the hope of the patient and their family.

#### **How to communicate a diagnosis: Liz Leff (US)**

Liz Leff is a kidney cancer patient from the [National Kidney Foundation \(NKF\)](#) in the US. When she was diagnosed, she was a single mother with a small child. The information that was being given to her was very confusing and made no sense. She didn't understand the terminology. This left her very scared, terrified, and nervous. This led her to a position at the NKF where she now helps support patients like herself.

The NKF came up with the idea to produce short educational videos to help patients understand complex information. They created 6 short videos (about 2 minutes long) for what is kidney cancer, diagnosis, surgery, immunotherapy, targeted therapy, etc. This has become a popular series with over 700,000 views both in English and Spanish, and nearly 400,000 patients watched the videos to the end. Three quarters of patients said the videos helped them to know what questions to ask their doctor or healthcare team. Healthcare professionals were able to use the videos to explain medical terminology to patients.

#### **Patient perspective, Eric Reguly (CA/IT)**

Canadian journalist and war correspondent, Eric Reguly, told his kidney cancer story. He was diagnosed 5 years ago in France. It was very frightening being diagnosed away from home. His first symptom was blood in his urine. He was in a lot of pain because of blood clots. He was told he had a bladder infection and was not scanned. He went home to Rome (he was living in Italy at the time) to see a urologist. He had a CT scan immediately and was told it could be cancer. The doctor was very blunt and direct. He was shocked. He had a large tumour and needed a radical nephrectomy. He found another urologist in Rome (who developed the da Vinci robot) and had a different experience. He had a biopsy but didn't know if the cancer had spread. The urologist looked him in the eye and was blunt but honest. This gave him confidence.

Catholic hospitals in Italy have priests and monks comforting the patients. The urologist came to see him with a monk and told him he was clear. He liked the way he was treated: The direct approach gave him confidence that he could deal with his cancer and made him feel he was going to get through it. He was spiritually uplifted by compassion, warmth, and care. He was discharged after 3 days and back at work after 10 days. He has follow-up scans every few months. Individual attention helped him get through the ordeal.

#### **Shared decision making, Deb Maskens (CA)**

Deb Maskens, Kidney Cancer Canada, spoke about the shift away from doctor-directed to patient-centred decision making since the 1990s. Treatment and care should be the patient's decision, considering values, preferences, and goals. Shared decision-making improves patients' satisfaction and there is less decision regret. It can also reduce healthcare costs, improve patient outcomes and is good practice. Informed decision-making is where the patient makes the primary decision after consulting the doctor(s).

Patients want full disclosure of information. Information should not be held back because of socioeconomic status, age, anxiety, geography, ease of access etc. Patients need doctors to give them relevant facts and numbers, not descriptions or anecdotes. Doctors should be careful about sharing success stories: This can make the patient feel a failure if their treatment is not a success. Patients need to know the percentage chance of a cure, side effects and what this means in their individual situation.

Challenges include lack of time (doctors are rushed), overwhelmed patients, guidelines for standards of care, conflicts of interest, latest treatment trends, and liability and malpractice concerns. Shared decision-making is a collaborative, ongoing process, involving doctors (and their team), patients, and families. Personal decisions should be respected, and decisions may change over time. All patients have the right to be informed about all possible treatment options.

In the IKCC 2018 Global Patient Survey 30% of patients were not involved in their treatment decisions whatsoever: "My doctor decided for me". Barriers to shared decision-making include lack of information about the disease, doctor's time and attitude, urgency to have treatment (anxiety), knowledge (language, literacy, and culture), fear of offending the doctor, uncertainties, personal situation (finances, logistics), and influence of family and loved ones. Patient organisations can help by recommending a second or third opinion when necessary and offering psychosocial support. Patients should tell the doctor what is important to them, what are their goals. When deciding on a treatment think about the Benefits, Risks, Alternatives and what happens if the patient does Nothing (BRAN). Patients and doctors need to balance quality versus quantity of life. The [IKCC has a group of decision aids on their website](#) to help patients with their shared decision-making.

## **Kidney cancer hot topics 2022 - Part 2**

*Moderator: Dr Rachel Giles (NL)*

*Discussion, Dena Battle (US), Deb Maskens (CA)*

### **Brain metastases, Dr Eric Jonasch (US)**

Dr Jonasch from MD Anderson Cancer Center in Houston, US, talked about how brain metastases differ from metastases in other organs and their treatment. Cancer cells float in the blood stream and lodge in other organs and grow to form metastases. Most common kidney cancer metastases are in the lung, lymph nodes, bone, and brain (2-15% of patients with kidney cancer). Treatment of brain metastases includes surgery and stereotactic radiotherapy (SRT). Collaboration between doctors and the patient voice is needed to improve treatment. There was a survey of 36 experts from 26 hospitals in 6 countries to share best practice. The survey looked at various aspects including diagnosis/screening and treatments. Based on their findings the team developed flow charts to manage kidney cancer brain metastases.

Routine brain MRI can be used as a screening tool, if available. Brain metastases are easier to treat if caught early. SRT or surgery is used for single or small numbers of brain metastases. SRT uses a beam of high dose radiation focused on the brain metastasis. This spares the healthy brain tissue surrounding the metastasis. For large numbers of brain metastases, whole brain radiotherapy is used only when all other options are exhausted. Hippocampal sparing can be used to protect the part of the brain for memory and cognition. Patients are followed-up with MRI or CT every 2-4 months. There are clinical trials for combination immunotherapies. Shared decision-making and a multidisciplinary team are the best way to manage patients with brain metastases.

### **The role for adjuvant and neoadjuvant therapy in kidney cancer, Dr Alessandro Volpe (IT)**

Dr Volpe discussed the role for adjuvant and neoadjuvant therapy for kidney cancer patients. More than 70% of patients have localised disease and there is a high chance of curing them with surgery. However, the cancer can return in up to 30% of patients after a nephrectomy (mostly within 5 years) and the risk of return increases to 60% in high-risk patients. Standard of care is surveillance based on risk of return of the cancer (stage, size of tumour, necrosis, spread to lymph nodes etc.).

Neoadjuvant therapy before surgery can reduce the size of the tumour making it easier to remove. It also gets rid of cancer that cannot be seen on a scan. Neoadjuvant therapy is in clinical trials and is not standard practice.

Adjuvant therapy aims to kill any remaining cancer cells after surgery. There have been 6 adjuvant tyrosine kinase inhibitor (TKI) trials for kidney cancer. Duration of treatment was mostly 1 year. The trials looked at cancer-free survival. Most patients were moderate- to high-risk patients. Adjuvant sunitinib did not show any difference in overall survival and is not recommended in treatment guidelines. Currently, there are no biomarkers to predict response, which would help select the patients who might benefit from adjuvant treatment. There is reduced quality of life due to side effects and high cost. However, it was approved for use in the US and a few other countries. In Europe, most oncologists don't recommend adjuvant sunitinib.

There are 4 adjuvant immunotherapy studies. Adjuvant pembrolizumab improved disease-free survival by about a third in moderate- to high-risk patients, or patients with a few metastases that were surgically removed during the first year after nephrectomy. The effect seems to last for at least 30 months. Overall survival difference is not yet known, but hints towards a benefit. The side effects for pembrolizumab were as expected. The EAU has made a weak recommendation for adjuvant pembrolizumab. Three other adjuvant immunotherapy trials (atezolizumab, nivolumab, nivolumab plus ipilimumab) have reported early results, and all are negative, meaning that taking any of those 3 immunotherapy agents for a year after surgery did not reduce the risk of the cancer returning.

In summary, side effects for adjuvant immunotherapy are like those seen with metastatic patients; however, they are less acceptable in patients who are mostly disease-free. Biomarkers are needed to predict who will benefit from adjuvant treatment, and patients need to be carefully selected based on clinical features. The use of adjuvant treatment needs discussion with the patient to share the decision.

In an IKCC poll of 149 patients, only 10% of patients would NOT take adjuvant treatment for high-risk disease. For patients with high-risk of recurrence, 40% would accept treatment provided it offered a 50% reduction in their risk of their cancer recurring. A second question in the poll asking patient opinion about the risk of needing steroids to control potential side effects of the adjuvant immunotherapy indicated that 40% of patients would accept adjuvant therapy if they knew the risk of having to take steroids was between 20-25%. Collectively these data suggest that patients are willing to accept some risks of adjuvant immunotherapy; however, it is important to note that for both questions, most patients required a lower risk than the data from the single adjuvant trial offered.

### **The role for adjuvant and neoadjuvant therapy in kidney cancer, Dena Battle (US)**

Dena Battle presented some early data from a survey of over 1000 patients from 28 countries, mostly the US (85%), conducted by KCCure. 36% had stage 3 disease and 18% were offered adjuvant therapy. 67% accepted, 19% declined and 14% were enrolled in a trial. Nearly half of the patients in the survey thought that their risk of the cancer coming back was higher than what their doctor thought. For most patients, they agreed that a decision needed to be made and wanted to be involved in the decision. Most doctors explained what adjuvant treatment was and there were high levels of shared decision-making (80-90%). For patients with high risk of their cancer coming back, they were prepared to tolerate the side effects and reduced quality of life to prevent this. Before we proceed with more adjuvant clinical trials, we need to identify which patients will benefit.

### **Patient perspective: Adjuvant therapy for RCC – are we there yet?**

Deb Maskens began by restating the unmet need for adjuvant treatments for RCC. Adjuvant treatments aim to delay or prevent recurrence of disease and are very much needed. The ideal adjuvant therapy would allow patient selection based on individual risk, provide a clear benefit, minimise toxicity and be affordable and accessible.

Since the early 1970s, many adjuvant therapies have been studied, but unfortunately nothing has worked. Radiation to the abdomen, chemotherapy, hormone therapy, shark cartilage, early immunotherapies (cytokines and vaccines) and TKIs (including sunitinib that was approved by the FDA) have all failed. Patient surveys suggest that 25% of patients would take adjuvant therapy if there was a survival benefit, and 60% would take it if it prolonged disease-free survival (yet only half of patients understood the meaning of disease-free survival or DFS.). Patients want to see a dramatic reduction in their personal risk.

Adjuvant immunotherapies have been tested in various trials, with only one trial showing benefit. Expected side effects of immunotherapy include the potential of severe or life-threatening side effects that often require the use of steroids. With adjuvant pembrolizumab, about 20% of patients experienced severe or life-threatening side effects and 20% discontinued treatment. Many patients who would otherwise be cured by surgery alone may have been over-treated. Approved in many countries, immunotherapy for one year comes at a high cost to health systems, insurance providers, or individuals. In addition, along with the medication toxicities there is the concept of time toxicity - a year of the patient and caregiver's life disrupted by adjuvant therapy.

Where does adjuvant monotherapy fit in the patient pathway? Kidney cancer experts have previously demonstrated that patients with early metastases can be observed or treated locally. When systemic therapy is appropriate, studies have shown that the best treatment for metastatic kidney cancer is combination therapy. Patients also need to consider how adjuvant therapy might impact their future treatment options. In some countries, if a patient takes adjuvant pembrolizumab and their cancer recurs during treatment or within 6 months of completion, they will not have the opportunity for combination therapy or potentially any further immunotherapy. Patients will also need to consider whether options for clinical trials will be open for those who have had adjuvant pembrolizumab.

In conclusion, while adjuvant pembrolizumab data looks encouraging thus far, it is important to remember that all other phase 3 adjuvant immunotherapy trials have failed to show any benefit, including nivolumab, atezolizumab, and the combination of ipilimumab plus nivolumab. Patients need to consider the very real risks of over treatment and life-long side effects that may impact their quality of life. Patient decision aids will help to make sure that each patient is fully informed and not taking this treatment because they over-estimate its benefits, under-estimate its risks, or are driven solely by anxiety or other pressures.

## **How people with cancer can benefit through the mindfulness-based recovery programme**

*Dr Linda Carlson (CA) virtual*

*Moderator: Christine Collins (CA)*

Dr Carlson is a professor of psychosocial oncology in Canada. A diagnosis of cancer can lead to a feeling of loss of control, threat to life, and a loss of certainty. It also leads to fear, anxiety, depression, as well as a burden on the family. Integrative oncology is a patient-centred, evidence-based field of cancer care that uses mind and body practices, natural products and/or lifestyle changes alongside usual cancer treatments. Integrative oncology aims to optimise health, quality of life and clinical outcomes, and empower patients to become active in their own care and treatment. She spoke about lifestyle activities such as exercise, diet, and sleep to manage stress. Mind-body therapies, such as mindfulness, meditation, yoga, acupuncture and Tai Chi/Qi Gong as well as natural health products like vitamins, minerals, and herbs under the supervision of an oncologist. She recommended a book called Anticancer Living by Lorenzo Cohen and Alison Jefferies introducing the concept of "Mix of Six", built on a belief that self-care is healthcare.

Mindfulness includes the whole patient, including mind, body, and spirit. Mindfulness is being in the present moment with an open and accepting attitude; a way of being in the world. About half the time, patients are not in the present moment, but can be happier if not worrying about the past or future. Let go of judgement, have patience and acceptance, be open and trusting. Being judgemental, impatient, and rejecting is the opposite of mindfulness and causes stress. When practicing mindfulness, breathing techniques can reduce tension, energy, and anxiety, causing relaxation to reduce stress. Mindfulness benefits are backed up by evidence and since 2018 there have been more than 1000 publications across all different conditions. Dr Carlson runs a 9-week mindfulness cancer recovery programme and has written a mindfulness-based cancer recovery patient manual (available in several languages). Research has shown that the signs of stress and quality of life improve throughout the course. The programme can be delivered online or via an app called the AM Dtx app.

## **Keynote Address: Managing renal disease and living meaningfully: The soul of medicine for patients and their healthcare providers**

*Dr Gary Rodin (CA) virtual*

*Moderator: Christine Collins (CA)*

Dr Rodin is professor of psychiatry and Director of the Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC) at the Princess Margaret Hospital and University, Toronto, Canada. His presentation focused on the neglect of the psychological care of cancer patients and that not enough attention is given to quality of life. He has developed a therapeutic programme called Managing Cancer and Living Meaningfully (CALM): A psychotherapeutic approach to early palliative care from diagnosis to death to help patients live longer and better. There is an imbalance between the biological aspects of care and the human side of medical care. Studies from US, France and China have shown that care at end of life is still mostly medical, not palliative.

Psychological burden of disease includes depression and demoralisation (25%), death anxiety, and stress. Most patients don't get psychological care. Psychological care in oncology tends to be reactive rather than proactive, and the evidence of the benefit of psychological care is lacking. The goal is to shift the balance from biology to the human side of medical care. The CALM course is 3-6 session over 3-6 months with ongoing weekly seminars. It is run by specially trained mental health practitioners. It is a form of early palliative care that enables patients and their caregivers to communicate their experience and address major decisions, burdens, and challenges of advanced disease. The CALM course includes disease management, looking closely at yourself and your relationship with others, identifying a sense of meaning and purpose, mortality, and future concerns.

Patients usually need psychological support when time is short, they lose dependency, and they have a fear of death. High levels of distress are a motivation for help, but patients don't get the chance to talk about how they are feeling. The goal is how to engage in life while facing end of life. Dr Rodin and his team have created a self-report scale of distress about death and dying, which is used in clinical care. About half of all patients have anxiety about death. CALM needs reflective space and time (when time is short) to face living and dying. Randomised controlled trials have shown CALM to reduce death anxiety and depression and increase spiritual wellbeing. Better communication with the healthcare team helps the patients prepare for the end of life. CALM is now available in 20 countries around the world. An online version is being developed called iCALM.

During COVID-19 support is extremely important, not just for patients, but healthcare providers. They created a programme to train healthcare professionals in supportive communications. They are now working on Project Empathy, a series of short videos to highlight and draw attention to oncologist-patient interactions and communication. They have created a digital information system called CancerSpace and they are improving the cancer centre to bring in art and music to have a soothing effect on cancer patients.

## **Nutrition: Supporting patients to live well**

*Juan Carlos Julian Mauro (ES)*

*Moderators: Christine Collins (CA) and Liz Leff (US)*

Juan Carlos from Federación Nacional ALCER spoke about a simple, easy to use handbook explaining the importance of a balanced diet for patients with kidney cancer related to the stage of their cancer. The project was a collaboration incorporating visions from professional societies in Spain, with national and international support. The book includes information about kidney cancer, attractive and tasty recipes, meal plans, a glossary and bibliography. It also addresses how to improve quality of life, reduce side effects with meals, and exercise tips. The guide can be used to improve diet, but the information must not be replaced by information from professionals. They have videos with professionals talking about diet and exercise and a website called NutriActivos.

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## **KCC patient advocacy group seeding project**

*Bryan Lewis (US)*

*Moderators: Christine Collins (CA) and Liz Leff (US)*

The IKCC is evaluating the creation of a patient advocacy group (PAG) seeding project. This project would provide modest financial grants to deserving affiliates, limited financial assistance to new start-up PAG's, or support existing affiliates with an objective to enhance collaboration and strengthen affiliate services to its community. An additional goal is to grow the number, capability, reach and strength of IKCC affiliates. Affiliates provided examples of projects that may be considered for funding support including:

- Translations, from English to local language, especially Ukrainian (or vice versa)
- Travel scholarships to international meetings
- Postage for leaflets to be distributed at hospitals/clinics
- Travel to hospitals to build relationships with urologists/oncologist/nurses/other health care providers
- Outreach efforts to patient populations to build awareness
- Provision of psychosocial support to patients.

The structure of this project is still under development. Policies and details about what types of projects are available for funding, an application process, and reporting requirements for this seed funding are early in development. It is anticipated that funding eligibility requirements will include a brief introduction of the applicant organisation, a description of the projects, any risks and unmet needs in the affiliate's country, the anticipated outcomes or outputs, how this project will benefit patients, and a project budget. Development of a task force comprised of affiliate volunteers and board members was recommended as a next step. Further recommendations to be brought forward for consideration.

## **DAY 3**

### **Breakfast session: Pan-cancer community working together in a time of crisis**

*Dr Rachel Giles (NL)*

Dr Giles spoke about how the cancer community comes together at times of crisis, such as the Ukrainian war, refugees, hurricanes, and financial crises. She asked the audience about their experiences: At the start of the Ukrainian war, charities and patient organisations were first to act. Charities suffered because most of the funding was going to the Ukrainian war effort and defence. This was most apparent in Finland and Poland, which border with Russia, and will have an impact on healthcare, education, and infrastructure over the next 10 years.

In Canada their healthcare system is in crisis following the COVID-19 pandemic. Most of Canada's healthcare is publicly funded. Screening, diagnosis, and treatment are delayed. Big fundraising events are tough, and donations are being made to patients with more pressing needs than cancer. The situation is similar in the UK, where patients are leaving the National Health Service in droves because of Brexit and COVID-19. State services are dissatisfied with low pay, high inflation, and high interest rates. There is civil unrest and strikes. Fundraising has dropped off a cliff because of the financial crisis and there is no government funding. In the US there is also civil unrest, uncertainty, apathy, and cyberattacks. We are stronger together, and collaboration within and between countries is needed in times of uncertainty.

The issue of climate change was raised and how much we add to the climate crisis. We need to think about which journeys are relevant and make more use of technology and virtual meetings. Travel less often, try not to fly, and combine meetings. Think about what is unique about the meeting you want to go to. Change in senior management and succession planning was also touched upon. An organisation is at risk when they lose their chair or CEO.

## **Patient support programmes**

*Speakers:*

*Flávia Kavalec, Instituto Oncoguia (BR)*

*Jin Joung Paik, Korean Kidney Cancer Association (KR)*

*Jyoti Patil Shah, V Care Foundation (IN)*

*Rachel Ruusma, Judy Nicholson Foundation (US)*

*Tadeusz Włodarczyk, Association GLADIATOR (PL)*

*Moderator: Bryan Lewis (US)*

### **Brazil: National support helpline**

Flávia Kavalec talked about the national support helpline Instituto Oncoguia have set up across Brazil to strengthen and guide patients living with kidney cancer. The helpline uses telephone, email, and WhatsApp. Patients get help from a personal support team with knowledge in oncology and patients' rights. The service is free, national, and confidential. Since COVID-19, the team have worked from home. There is also access to an online psychologist. Most patients make contact via the website. Most concerns are delays in diagnosis, questions about legal rights, finances, quality of life, surgery, access to medication in the public health system, suspension of treatment, lack of follow up after surgery, and clinical trial participation.

### **Korea: Kidney cancer treatments**

Jin Young Paik from the Korean Kidney Cancer Association talked about kidney cancer treatment in Korea. Korea has a national health service, and cancer patients pay 5% of their treatment expenses. There is patient financial support nationally and from local governments. Early detection is increasing and the age of patients decreasing due to the health examination system. There are negative perceptions about clinical trials. It is difficult to get information and to take part. Patient groups can help with this. There are numerous anti-cancer medicines being approved, but few are reimbursed. Patients can't pay for these treatments, and they demand reimbursement. Return to daily life is difficult. Patients need to be embraced as members of the community. Tips: always join a patient group, seek a second opinion, check for clinical trials, make notes of questions, get psychological help, and make a life plan.

### **India: Patient support programme**

Jyoti Patil Shah from V Care Foundation talked about their patient support programme. They strongly believe in empowering patients. Emotional support is particularly important. They help patients with access and cost of treatment (mostly sunitinib), decision-making, and waiting times (doctors sees more than 100 patients a day!). They have patient navigators to help bridge the gap between patients and doctors. There are not many clinical trials in India, and it is difficult for patients to understand them. V Care help with patient-friendly information and explain the pros and cons. Emotional support is listening to the patient and guiding the patient through the hospital logistics. Early diagnosis is difficult in India. Palliative care does not always mean end of life, but quality of life.

### **US: The mission of the Judy Nicholson Foundation**

Rachel Ruusma introduced the Judy Nicholson Foundation. The foundation is dedicated to getting rid of death and suffering from kidney cancer. The foundation promotes research, education, support for patients and families and serves as an advocate on behalf of patients with the US government. They have educational symposia delivered by doctors for patients and caregivers, online and face-to-face. They have a YouTube channel with yoga and nutritional support, gatherings for caregivers, webinars and symposia on cancer, nutrition, and exercise. They run face-to-face events across US.

### **Poland: Patient support programme**

Tadeusz Włodarczyk introduced the GLADIATOR Association. GLADIATOR started in 2002 with a helpline, mostly focused on prostate cancer. The first reaction of patients is panic, even without having results. They have produced a set of information brochures and collaborated with psychologists and doctors. The helpline is their main service. They learned how to support patients over time and with experience. They send printed materials directly to

patients and have patient meetings, including doctors to help educate patients. They now work with over 50 specialists, and patient meetings include 2-300 people, including family members and friends. During the pandemic, meetings were not possible and online meetings are difficult in Poland, so they used printed materials, website, and Facebook. During the pandemic, the helpline became especially important. They are also trying to encourage the ministry of health to approve new drugs.

## **The Cecile and Ken Youner IKCC Scholarship**

### **Evaluation of renal cancer care in Canada during COVID-19 pandemic**

*Dr Jesus Cendejas-Gomez (MX/CA)*

*Moderator: Dr Eric Jonasch (US)*

Dr Jonasch announced the winner of the Cecile and Ken Youner IKCC scholarship for 2022. 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 Summit to present their work on kidney cancer 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 fifth awardee.

This year the award goes to Dr Jesus Cendejas-Gomez, a urological fellow from Mexico who is now doing a uro-oncology fellowship in Western University in London, Ontario, Canada. His project is studying the care patterns of newly diagnosed kidney cancer patients during the COVID-19 pandemic in Canada. Hospitals had to adapt to the pandemic and prioritise patients due to shortages of beds and ventilators. Surgery and treatments were delayed or cancelled, and waiting times were longer. He uses databases to look at how COVID-19 has affected the outcomes of kidney cancer patients in Canada. The survey is ongoing, and he will compare outcomes pre- and post-pandemic.

## **Access to treatments: Challenges and opportunities**

*Moderator: Dr Michael Jewett (CA)*

Dr Michael Jewett introduced this session with a heart-breaking video about a child who underwent treatment of a rare kidney cancer in South Africa. Most paediatric kidney cancer goes undiagnosed and untreated. Families must travel miles for treatment visiting different hospitals, and many children die. Advances in cancer care mean nothing if patients are not able to access it. [Wings and Wishes](#) is a South African non-governmental organisation dedicated to transporting critically ill children so they can receive life-saving treatment. This set the stage for discussions of disparities and other problems in global kidney cancer care.

## **Generics and biosimilars, Julie Jenson, Pfizer**

Julie Jenson is in the Global Public and Corporate Affairs team at Pfizer. Pfizer was approached to present about issues and possible opportunities with Sutent coming off patent. Pfizer have programmes in lower income countries, 80% in Africa. Most of their programmes are for HIV, infectious diseases, and COVID-19. They are now looking at cancer and rare diseases in these countries. The problem goes beyond drug availability as frequently the systems to introduce a new drug are not in place. In high income countries there are clinical trials, new drug applications, and regulatory approval before the drug is available. Their health systems have some familiarity with the new drugs. Patents can last for 12 or more years, at which time generic drugs can become available. In low- and middle-income countries, patients don't have access to clinical trials and there is no regulatory system. New medicines are frequently not sold in these countries and some doctors are unaware of the medicines. Low- and middle-income countries are therefore at least 12 years behind high-income countries. There is no supply chain for generics in these countries. Pfizer are trying to build capacity in clinical trials to give patients access to new medicines, including generics. They make donations to the health system to train doctors and send medicines not for profit. The government can then buy generic medicines when available.

Caleb Egwuenu from Move Against Cancer Africa spoke about the situation in Nigeria as well as Africa in general. Doctors need to be careful that generic medicines are really what they say they are. The pharmacies profit from counterfeits. A system is needed to make sure that patients are not getting fake medicines. The gap between low- and high-income countries needs to be reduced and the regulatory systems in low-income countries strengthened. Generic medicines are also not affordable for most patients in low-income countries.

### **Access to treatments for kidney cancer patients in low- and middle-income countries, Alicia Annamalay, The Max Foundation**

Alicia Annamalay introduced the work of the Max Foundation. The Foundation started 25 years ago. Their mission is to accelerate health equality by delivering medication, technology and services to patients who do not have access to these services. The Max Access Solution programme channels life-saving treatment to low- and middle-income countries. They also have Health System Strengthening and Social Determinants programmes for advocacy, transportation, and psychosocial support. They focus on healthcare providers, patient advocates, shipping, and logistics. They have a global supply chain that allows them to deliver medicines directly to patients. To date they have supported 90,000 patients, mostly blood cancer patients. Recently, they have included kidney cancer patients. Partnership with Pfizer has enabled access to 3 kidney cancer medicines (sunitinib, axitinib and temsirolimus) and they have supported 847 patients from 21 countries. To ensure accessibility, they need to break down health literacy barriers, culture barriers, and practical barriers (e.g., transport to clinic). Most kidney cancer patients present at a late stage. Generics are not generally available and patient groups are scarce. IKCC patient groups can support with training, advocacy, diagnostic capacity, and access to medicines.

Mariam Izoria is a medical doctor and epidemiologist from the Max Foundation based in Georgia. She gave a brief overview of the situation in Georgia regarding diagnostics and availability of treatments. Sunitinib is covered by government health insurance, but only for two months. After that the price is \$3,000 per cycle and it is very difficult for patients to pay. Patients stop taking sunitinib resulting in poor outcomes. The Max Foundation supports 6 patients with sunitinib, but new patients are being rejected from the programme.

### **Access to essential cancer medicines: The Desert Island Project, Dr Christopher Booth (CA) virtually**

Dr Booth, professor of oncology at Queen's University in Kingston, Ontario, Canada, talked about access to essential cancer medicines and a project he is leading called the Desert Island Project. In his and many other oncologists' opinions, there is a crisis in value in global cancer care. The use of the most common clinical trial endpoint of progression-free survival (the time to when the drug stops working, and the cancer starts growing again) has resulted in the approval of some very expensive medicines with little survival benefit plus toxic side effects. The price of cancer medicines has shot up over the past decade and typical cancer medicines cost in the range of \$150-300,000 per year (accompanied by a 70% increase in pharmaceutical income from cancer medicines). Most of these medicines are not available worldwide.

To help patients live longer and enjoy better lives, Dr Booth strongly supports the use of overall survival and quality of life endpoints. This is what patients value. Many drugs have a lot of side effects. Progression-free survival gives an early indication of survival but is not related to quality of life. Are these medicines giving patients value of care, especially when the cost of the medicine, infusion time, travel, and age and health of patients are considered in the real world? The medicines with the smallest benefits seem to have the highest price.

The Desert Island Project surveyed oncologists around the world and asked them to select 10 cancer medicines they need to treat patients in their countries. There were 1000 oncologists from 82 countries in the survey. The top 20 medicines that were chosen were old fashioned chemotherapies and hormones that have very large benefits. There was consistency between high- and low-income countries. This raises the question of whether the essential medicine list from the World Health Organisation reflects what is happening in the real world. The essential medicine list reviews the benefits and harms of medicines and guides the purchase of medicines, particularly in countries without a health technology assessment. Most of the medicines in the project were still unavailable and expensive for most patients in low- and middle-income countries. There is limited availability, even for generics, so how can we advocate for new more expensive treatments?

Global mindsets need changing. There is a lot of media hype and unrealistic expectations. We need to ensure access to safe, affordable, and effective care. Healthcare needs to be regulated to avoid being seduced by new technologies that may not be as beneficial as old treatments. There is a crisis in the value of cancer care. We need to ensure all patients get the treatments that really matter, and we should not settle for expensive, toxic therapies with little benefit: Patients deserve better.

### **End of conference remarks**

*Dr Rachel Giles (NL)*

Matilda Osterberg a kidney cancer patient from the Swedish Kidney Cancer Association, closed the meeting. This was her first time at the IKCC conference. It was very inspiring for her to meet everyone and learn what has been done. There are a lot of available resources and ideas, and it was very inspiring to hear from other patients. Everyone was very generous with their advice. She thanked the medical professionals and was very grateful for those who gave up their time to be at the meeting. She is very excited to see the results of the COVID-19 survey.

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.

Dr Giles thanked all the affiliates for attending. The quality of the meeting reflected the input from the affiliates. She then went on to thank the audio-visual team, and Julia Black and Annika Marshall for organising the meeting. Finally, she thanked everyone on the organising committee.

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