



Global Kidney Cancer Summit 2021

24th and 25th September

IKCC Global Kidney Cancer Summit 2021

This year the primary focus of the IKCC Global Kidney Cancer Summit was connection. In a time when being together still isn't possible, affiliate organisations came together virtually to build, maintain, and strengthen connection throughout the global kidney cancer community.

DAY 1 – Friday 24 September 2021

Welcome to the IKCC Global Kidney Cancer Summit

IKCC Chair: Dr Rachel Giles (NL)

This was the 11th IKCC Global Kidney Cancer Summit. Ninety-four (94) people from 23 countries registered to take part (58% patient representatives, 25% patients, mostly from Europe and North America). The last year and half have presented challenges for most organisations, which have had to adapt to working through the COVID-19 pandemic. This meeting is intended to be interactive so that affiliates can learn from each other and help each other, share our successes and challenges, and help build capacity across the network to focus on reducing the burden of kidney cancer.

We are grateful to the IKCC 2021 Conference Committee for their dedication to the planning and organisation of this year's global summit. Committee members include Linda Anderson (USA), Vandana Gupta (IN), Dr Michael Jewett (CA), and Linda Ostoski (USA).

ESMO 2021 Highlights

Moderator: Dr Michael Jewett (CA)

Dr Andreas Michael Schmitt (UK), Clinical Research Fellow, Royal Marsden Hospital, London

Dr Schmitt gave a summary of the highlights from this year's European Society of Medical Oncology (ESMO) conference, which took place virtually from 16-21 September 2021. For full highlights, please see the [IKCC website](#).

Belzutifan plus cabozantinib for advanced clear cell RCC

Kidney cancers frequently have mutations in the von Hippel-Lindau (VHL) gene, resulting in high levels of a protein called hypoxia-inducible factor, or HIF-2 α , which favours tumour growth. The novel hypoxia-inducible factor 2 α (HIF-2 α) inhibitor, belzutifan (MK-6482), blocks the action of HIF-2 α .

This presentation updated the results from an ongoing phase 2 study, where the safety and efficacy of belzutifan in combination with cabozantinib was assessed in people with clear cell renal cell carcinoma (RCC). More than a quarter of patients (29%) responded to treatment and the disease was controlled in 92% of those patients. The average time to when the treatment stopped working and the cancer started growing again (progression-free survival) was 16.8 months and 81% of patients survived at least one year. Almost all patients had tumour shrinkage in the beginning. Nearly all patients (98%) had a treatment-related side effect, although most (92%) were mild or moderate. There were no life-threatening side effects or deaths related to treatment.

Belzutifan showed promising anti-cancer activity when given with cabozantinib in patients with metastatic clear cell RCC that had been previously treated. More follow-up data are needed to calculate overall survival times and belzutifan needs to be compared with standard treatments to define its place in the RCC treatment pathway.

Pembrolizumab as an adjuvant therapy

Nephrectomy is the standard of care for localised RCC; however, the cancer can come back (recurrence) after surgery in about half of all patients. Adjuvant therapy is treatment that is given after surgery to try to prevent the cancer from coming back. The phase 3 KEYNOTE-564 trial looked at the use of pembrolizumab as an adjuvant therapy for patients with clear cell RCC after nephrectomy. Patients were randomly allocated to be given either pembrolizumab or placebo for one year and monitored for return of their cancer. Pembrolizumab significantly reduced the relative risk of the cancer returning by about one third (32%). More follow up is required to make any definitive conclusions about overall survival.

Patients were asked questions about their quality of life at the beginning, during and at the end of the study. There was only a slight deterioration of quality of life for patients treated with pembrolizumab compared to placebo, but this was not statistically significant. Importantly, quality of life remained stable over time. Patients reported that pembrolizumab was tolerable from a patient perspective.

These results suggest that quality-of-life does not substantially suffer if pembrolizumab is taken for up to a year after surgery. However, the use of an adjuvant treatment needs to be discussed carefully with each patient to make them aware of any potential side effects.

Alternative treatment schedule for ipilimumab/nivolumab in first-line treatment of advanced RCC (PRISM)

The combination of ipilimumab plus nivolumab for previously untreated metastatic RCC can cause serious or life-threatening side effects, which are mainly caused by ipilimumab. The aim of this phase 2 trial (PRISM) was to see if changing the treatment schedule for this combination can make this treatment more tolerable without affecting patient survival.

Patients were treated with ipilimumab plus nivolumab every 12 weeks for four doses with nivolumab every 2 weeks between combination doses and compared with the standard treatment schedule of ipilimumab/nivolumab (ipilimumab plus nivolumab every 3 weeks for the first 4 doses followed by nivolumab every 2 weeks). Serious or life-threatening side effects were significantly lower in the patients on the modified ipilimumab schedule compared to the standard schedule (32.8% versus 53.1%, respectively). There appeared to be no survival differences for patients on the modified treatment schedule.

This study showed that giving ipilimumab every 12 weeks instead of every 3 weeks, in combination with nivolumab, significantly reduced the number of serious or life-threatening side effects to treatment. The change in treatment schedule did not seem to affect the survival outcomes of the patients but the trial is too small to draw firm conclusions from this.

Organisational successes, challenges, key initiatives, and best practices

Moderator: Vandana Gupta (IN)

Dena Battle (USA): Recognising & addressing health related information and misinformation on social media

Dena Battle from KCCure in the USA talked about the harm caused by misinformation on social media. Medical misinformation has been around for a long time; however, since the advent of social media, the use of misinformation has increased dramatically, and is set to rise to 54% by 2025. Types of misinformation include predictably selling, conspiracy ideation (blogs, Facebook groups, papers), inflammatory news stories presented in a biased way, and fake news. A survey reported that 80% of cancer patients use social media to connect with peers. Facebook alone has 6 million health related groups and 20+ active kidney cancer groups. A survey in 2018 reported that more than half (52%) of the information on social media was false or misleading, and nearly half (47%) of health-related information was trying to sell services. 43% of medical or health-related studies seemed to contradict each other. However, around 70% of kidney cancer stories were found to be accurate.

In conclusion, social media is the dominant source of information for cancer patients today and there is rising concern about the accuracy of this information. Misinformation about kidney cancer exists but is poorly characterised. More research is needed to determine the effect of sampling bias (i.e., do patients in a trial accurately represent the overall patient population). Current definitions of misinformation need to be expanded to improve patient awareness.

Dr Rachel Giles (NL): The first national Standardised Care Pathway for patients with VHL

Dr Giles also runs the Dutch VHL Organisation. Von Hippel-Lindau (VHL) disease is a rare hereditary condition that affects 1 in 36,000 births worldwide. It causes tumours to develop in the brain, spine, eyes, adrenals, testes, pancreas, kidneys, and uterus. Patients need to be scanned constantly and tumours removed surgically. It is a life-long condition and the most common form of hereditary kidney cancer. In the Netherlands there are 375 patients with VHL, 300 of whom belong to the Dutch VHL Organisation.

The Dutch VHL Organisation has been involved in the development of a patient-driven care pathway, that considers various criteria, such as: the recognition of VHL as a chronic condition by the healthcare provider, a dedicated specialist nurse for each patient to improve awareness and coordinate care and treatment between the GP and hospital specialist, extensive verbal and written information for both patients and carers, expert centres, and multi-disciplinary consultations.

The Dutch VHL Organisation has been successful in developing a set of patient-driven recommendations for the care and treatment of VHL patients throughout their journey from referral to follow up. So far, this care pathway has been implemented in the 2 centres in the Netherlands who see the most patients. This is an example of a co-created care pathway for a complex tumour syndrome being implemented at national level.

Joshua Mann (USA): Organisational success, challenges, and key initiatives during the pandemic

Joshua Mann from the VHL Alliance in the USA spoke about their organisational successes, challenges, and key initiatives during the pandemic. Organisational successes included the use of social media to promote and host events increasing the range of programme offerings and patient engagement, an updated VHL handbook, an intern programme, and expansion of their Clinical Care Center provider network globally (multi-disciplinary teams of specialty doctors and researchers). They also had the first drug for VHL approved by the FDA in August 2021.

Challenges for VHL Alliance have been the transition to remote working, addressing the changing community needs, fundraising, Zoom fatigue, addressing community concerns about COVID-19 and vaccines, and access to specialty care and ongoing surveillance. During the pandemic they introduced some key initiatives, such as a surviving and thriving together programme, a virtual VHL tumour board, a wellness coaching programme, a retreat for young adults, an annual VHL family meeting, an international VHL medical research symposium, a hotline, a pen pal programme, a patient registry, and regional meetings.

The Cecile and Ken Youner IKCC Scholarship Award

Dr Eric Jonasch (Vice Chair of the Medical Advisory Board) announced the winners of the Cecile and Ken Youner IKCC Scholarship. It was difficult to select one recipient of the prize this year, so the scholarship was awarded to both Dr Charlotte Spencer and Dr Elshad Hasanov:

Dr Charlotte Spencer from The Francis Crick Institute, London, UK was awarded the prize for her work on the characterisation of the histological appearance of genomic alterations in clear cell RCC, and harnessing machine learning to predict genetic mutations to ultimately predict patient outcomes.

Dr Elshad Hasanov from the University of Texas MD Anderson Cancer Center, USA was awarded the prize for his work on the molecular characterisation of RCC brain metastases from genomic features and nucleus sequencing and comparing them with other metastatic sites.

Many congratulations to both Dr Spencer and Dr Hasanov for being awarded this prestigious scholarship to enable them to continue with their vital research.

Reaching and engaging new patients and carers

Moderator: Linda Anderson (USA)

Christine Battistini (BR): Awareness campaigns and how to engage patients

Christine Battistini from the Instituto Espaço de Vida in Brazil gave a unique live presentation about their Pink October awareness campaign for cancer patients. The aim of the campaign is to ensure patients are aware of their services and that they feel part of the programme. They used infographics to engage patients to be part

of the process. The key to engagement is to make patients feel special, and to use real people, short video clips and real stories on social media make patients feel part of the creative process and let them know you care. To attract attention, stories/videos on social media need to be short and catchy.

Jyoti Shah (IN): Enabling technology in reaching out to patients and caregivers

Jyoti Shah from the V Care Foundation in India described their patient access programme to empower patients with the right tools during the pandemic and to provide them with support and access to treatments. During the pandemic, hundreds of patients attended one of Asia's biggest hospitals every day. They set-up a hotline for virtual consultations. V Care collaborated with the hospital to distribute treatments to patients via courier using virtual prescriptions via WhatsApp. They also used Zoom and FaceTime for virtual meetings with patients. Using these technologies, they connected regional cancer centres and partnered with hospitals for webinars.

Emma Andersson (FI): Reaching out to patients – Story of the kidney cancer patient guide

Emma Andersson from the Association of Cancer Patients in Finland described the publication of a kidney cancer guide and reaching out to patients and hospitals with the guide. The Association of Cancer Patients in Finland co-designs activities and materials with cancer patients and carers. They also engage in patient advocacy, provide patient support and moderate 25 Facebook groups with 9,200 patients. They have produced 40 patient guides in Finnish and Swedish, some in English and Russian, and a few as audiobooks. Some guides are specific to different types of cancer, while others focus on thematic issues, such as fatigue, sexuality, caregivers, return to work etc. A common format for most patient guides is that they contain information on the cancer type, treatments, tips for coping with the illness as well as a glossary. The guides are currently undergoing an update process in terms of content and layout/design. The guides are available as hard copies or electronically and are shipped to hospitals, patients, and member associations of Cancer Society of Finland. The new kidney cancer guide will be available in Finnish by the end of the year.

Linda Ostoski (USA): Giving patients and caregivers what they ask for

Linda Ostoski from the Judy Nicholson Foundation in the USA spoke about a celebration of life and hope. The Judy Nicholson Foundation provide support and information for kidney cancer patients and caregivers. Since the pandemic, they organise virtual meetings, webinars, share articles through social media, and videos, rather than face-to-face events. Nutrition, loneliness during COVID-19, and fitness are popular topics. Doctors conducted their consultations virtually during quarantine, but patients didn't feel connected. Caregivers can get support from a dedicated online support page from the Judy Nicholson Foundation. The Judy Nicholson Foundation have partnered with several other kidney cancer groups to provide enhanced support for kidney cancer patients and their caregivers.



DAY 2 – Saturday 25 September 2021

Strengthening patient support programmes to cope with a diagnosis

Moderator: Bryan Lewis (USA)

During this session, perspectives from four patient group leaders from around the world were presented then followed with discussion.

Meredith Kruse (BR): Instituto Oncoguia

Instituto Oncoguia is a patient advocacy organisation from Brazil that provides quality information, support, advocacy, and health education to guide patients through their cancer journey and stand up for patient's rights. This year, they are involved in an awareness campaign about quality of life and kidney cancer treatments, an educational debate with urologists and oncologists (OncoDebate), and the launch of a kidney cancer charter for Brazil. They are also working with the ministry of health for access to first- and second-line kidney cancer treatments.

Christine Collins (CA): Kidney Cancer Canada

Kidney Cancer Canada (KCC) supports and educates communities and advocates for better treatments and care for patients. They aim to improve the lives of those affected by kidney cancer across Canada (English and French) through peer support, advocacy, research, and information. Support is provided in several ways, from virtual coffee chats that reach isolated and remote communities, educational webinars on mental health, mindfulness, diagnosis and treatments, surveys, petitions, policy decisions and collaborations to ensure the patient voice is heard and respected. They also provide funding for the Kidney Cancer Research Network of Canada, a collaboration of Canadian doctors and researchers with an interest in the causes and treatment of kidney cancer.

Athina Alexandridou (GR): VHL Family Alliance Greece

VHL Family Alliance Greece is a non-profit organisation supporting 45 families with VHL in Greece. Each family has 10 or more members with VHL disease. VHL Family Alliance Greece provides information, research, and medical knowledge. They aim to identify every patient in Greece with VHL disease through DNA testing and identify all cases of VHL kidney cancer. They aim to build awareness of early detection and monitoring with doctors and patients, educate every doctor about VHL and how to detect VHL, and build awareness of new therapies and clinical trials. They want equality of access to treatment and care, psychological support, and to remove the stigma from the lives of people with a rare disease via education with leaflets, including one directed at children.

Susan Poteat (USA): KidneyCan

KidneyCan was formed by patients who were connected via Smart Patients. It is a 5-year-old, patient-driven organisation, which advocates for government funds for research and patient education. They hold a kidney cancer research summit (KCRS) annually based on the grants provided by the government for kidney cancer research. To date, with extensive help from the greater kidney cancer patient community, they have successfully advocated for \$50 million in 2021 for research. Three years ago, they reached out to doctors, laboratory and clinical researchers and convened a basic and translational research focused meeting. They also advocate for patients by providing support, resources, education, and connections. Their emphasis is to understand kidney cancer, build care teams, identify new treatments and trial options, so that people can live well with kidney cancer and eventually accelerate a cure for kidney cancer.

Ways to support carers

Moderator: Belinda Jago (AU)

Robin Martinez (USA): Smart Patients

Smart Patients has been around since 1995. It is a free private moderated forum where patients and family members learn from each other. Many of the communities are cancer patients/carers, and kidney cancer is one of the largest communities. There is intimacy and anonymity within the communities. All posts are moderated and inappropriate posts blocked and taken down to protect communities. The communities are English speakers from all around the world. They share medical information, guidance, information, joy, and

despair. Carers need everything provided to patients and more to give their loved one the best chance of life. Carers need as much support as patients and have their own group on Smart Patients to enable them to speak only to other carers. There are private messages for sensitive topics. This is a wonderful large group of long-time survivors and carers sharing what they have learnt.

Carlos Castro (MX): Asociación ALE

Asociación ALE is a non-profit organisation promoting organ donation and transplantation throughout Mexico. They are advocating for a national carer's system. There are 6 million disabled people in Mexico (6.2% of the population) and less than 1% are in a private institution. The vast majority remain at home with unpaid care. With an aging population, and low pension, the situation needs addressing. 70% of carers are female, usually unemployed daughters or wives. There is no carer's policy in the Mexican social security system, and most people who need help do not have a carer. In August 2018 the National Board for Health agreed to establish a policy for long-term carers, but nothing has been done since. Asociación ALE are lobbying for change in public policy for a new care model, supported almost entirely by family, most of which are poor. These people will need training in basic care, as well as a financial incentive to give up fulltime work to take on a carer role. It will be a great challenge but is achievable with political will and the appropriate budget.

Ankita Ambolkar (IN): V Care Foundation

In India, it is often a family member who looks after the sick or elderly at home. They need to understand the role of a carer, learn to ask for help, understand the diagnosis, stay positive, join online support groups, enlist others to help, be aware and understand their feelings, and stay organised and take care of themselves. Talk to the doctor, read up on the disease, understand side effects of treatments, and seek a second opinion – this can make the carer feel more confident. It can be hard to stay on top of things, e.g., hospital appointments, so make lists and ask for help when needed. An optimistic outlook can help motivate patients. Try to understand what the patient is going through. Carers may feel sad, angry, grief, loneliness – seek help to uplift your spirits and take care of yourself, both physically and mentally. It is OK to take breaks and have a personal life. Support group meetings can help, as can hobbies and socialising. Connect with others online. Use telemedicine to connect with doctors – this enables the patient to talk to the doctor from the comfort of their own home, thereby reducing the stress of hospital visits.

At the end of this session, there was discussion about financial support for carers and the financial toxicity associated with a cancer diagnosis. In the USA, there are health insurance policies, but these are usually only for the patient. Some programmes, such as Medicaid, provide care for family members at home, but only the patient can benefit financially. The Veterans Administration provides home care for ex-servicemen. In the UK there are several programmes for patients and carers. There is a carers allowance for people on benefits or a low wage, community outreach from the NHS, and a carer's respite programme where the patient can go to a hospice/hospital to allow the carer a break.

Impact of the pandemic on the kidney cancer community

Moderated discussion

Alex Filicevas (BE): World Bladder Cancer Patient Coalition

The World Bladder Cancer Coalition took part in two COVID-19 surveys; in June 2020 (157 patient organisations) and December 2020 (104 patient organisations). The survey was used to determine experiences and best practices, and to see how this changed in the 6 months from June to December. The patient organisations represented different cancer groups worldwide. In June 2020, two thirds of patient groups had paid staff, the remaining groups were run by volunteers. In December 2020 there was a drop of 18% in paid staff and 70% in volunteers, resulting in a decrease in capacity for patient support. Two organisations closed permanently and 13 paused services temporarily. Most services were changed from in-person to online and COVID-19 information increased. Two thirds of organisations had a fall in income, the average fall being 48%. 79% predict even less income in 2021. All fundraising activities were affected, mostly in-person events, public collections, and community fundraising. For one in ten organisations, their viability is threatened and for a third of organisations, their future is uncertain. Emergency support is needed for these organisations, and collaboration with governments to restore cancer services.

Sallie McAdoo (USA): Kidney Cancer Association

In the US, there was a 25% decrease in private and federal/corporate donations. Funding was re-directed to COVID-19 research and industry tightened their budgets. The pandemic affected research: laboratory research was repurposed, there was staff burnout causing reduced productivity, researchers were not allowed into laboratories, and training suffered. There was limited access for non-essential testing. Clinical trial enrolment was down almost 50%, and 60% of trials stopped enrolment. There was loss of interaction at conferences due to virtual access only. Reduced access to research centres led to telemedicine and decentralised care. Loss of patient empowerment led to higher drop out from trials. There is now more focus on patient communication and different approaches to consent. However, all this led to less paperwork, flexibility and shared databases leading to better real-world data and novel trial designs.

Reduced access to healthcare resulted in later diagnosis of cancer and a disruption to clinical flow (follow-up, staff changes, delayed appointments). There was uncertainty of care, especially regarding immunotherapy and vaccination. There was disparate use of telemedicine due to access and comfort with use. Family members could not visit loved ones in hospital, which affected care. Most people experienced hardship in terms of balancing the risk of cancer with the risk of COVID-19. The Kidney Cancer Association extended their research grant programme, there was less conference support, and they increased healthcare education online. They increased their staff for remote support programmes, online resources, and psychosocial support.

Juan Carlos Julián Mauro (ESP): ALCER

ALCER conducted a survey of kidney cancer patients in Spain during the first and second wave of COVID-19 infection during April and December 2020. The need for psychological care due to the pandemic decreased from 41% in the first wave to 31% in second wave (three quarters of whom were women). More than three quarters of patients were pessimistic about the pandemic, again mostly women. Men tended to be more optimistic. Nearly two thirds of patients enjoyed life less than before the first wave of the pandemic – this had declined to less than a half in December 2020. Emotional distress was higher in younger patients and families (57% versus 24% for patient over 65) and affected daily life more than anything else. Nearly a third of patients said the pandemic had affected their social life and 20% their job. A third of patients would prefer to speak to their family and just over a quarter would prefer to speak to other kidney cancer patients. This contrasts with the rest of the world where 68% preferred to talk to other patients.

Closing remarks

IKCC Medical Advisory Board Chair: Dr Michael Jewett (CA)

IKCC Chair: Dr Rachel Giles (NL)

Dr Giles thanked everyone for their attendance and Dr Michael Jewett reviewed the IKCC Medical Advisory Board membership and planned activities:

The Medical Advisory Board (MAB) provides high-level scientific and clinical expertise to IKCC. This ensures that the organisation provides evidence-based leadership within the international kidney cancer community that includes all those involved in kidney cancer treatment care, research, and advocacy, as well as patients and caregivers. In addition, the Medical Advisory Board represents and advocates for patient values and perspectives in major scientific committees and expert groups at both national and international levels. The full MAB membership can be found on the [IKCC website](#) and is composed of oncologists, surgeons, and a nurse with an interest in kidney cancer.

The MAB has been invited to present a lecture on kidney cancer advocacy at the upcoming EAU Congress scheduled in Amsterdam in March 2022 as a podium plenary presentation. This lecture is a trial initiative intended to advocate for clinicians to better recognise the importance of engaging patients and their cares in management. A very preliminary plan to host a workshop for clinicians to better understand the role of patients and advocacy in cancer care is being evaluated as well. These two initiatives are new for the MAB and will be exciting to evaluate.

End of conference