



# BOOK OF COURAGE AND HOPE

Kidney Cancer  
Patient Stories  
From Around  
The World

# Introduction

Thank you to the kidney cancer patients, caregivers, and families who are featured so beautifully throughout this “Book of Courage and Hope”. Sharing personal stories takes tremendous courage. Each story is an amazing testimony to the courage and unique challenges faced by kidney cancer patients and their caregivers.

Around the world, kidney cancer patients share a wide range of challenges – not only with different subtypes and stages of disease, but often with inequitable and complex health systems in their home countries. The determination of individual patients to push for better treatment options, to demand better care and support their fellow patients is truly remarkable. On behalf of the International Kidney Cancer Coalition (IKCC), we owe these patients and their families our deepest gratitude.

The IKCC “Book of Courage and Hope” also illustrates our belief that being a part of a cancer patient support group and sharing knowledge and experiences with each other not only helps individual patients, but can also serve more broadly to increase knowledge of unmet medical needs, raise awareness, and foster further research in kidney cancer.



If there is an underlying theme that runs through most of our patient stories, it is one of fellowship and an innate understanding that it is often patients who are best motivated to help improve the lives of other kidney cancer patients both now and in the future. Through their personal advocacy and generosity of spirit, our patients underscore the need for more research, for more holistic person-centred care, for better information and support and sometimes just for simple pain relief.

By publishing this book, the IKCC hopes to demonstrate the breadth and diversity of the global kidney cancer community and, along with our Affiliate Organisations, our shared belief that "Together we are stronger".

We welcome your feedback on this publication:  
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*The stories, views and opinions contained in the kidney cancer patient stories are those of individual patients and/or caregivers and do not necessarily reflect the views and opinions of Stichting IKCC, its Board Members or its Affiliated Organisations.*

*The information in this book is not intended as a substitute for consultation with healthcare professionals. Each individual's health concerns should be evaluated by a qualified healthcare professional.*

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*The IKCC Board of Directors*

## The Power of Patient Organisations

*By Markus Wartenberg*

**Cancer patient organisations around the world carry out enormously important work on behalf of patients and their families. Without them, the standard of care and support available to cancer patients would be severely compromised in some countries. Doctors and nurses increasingly find themselves in the position where they cannot give patients the care and attention they deserve due to time and financial restraints. Patient organisations not only offer patients and their families information and support, but also the individual care and attention many hospitals are unable to provide. In today's economic climate, patient organisations come into their own by offering practical patient support, and take on the role of advocates for best quality health care, access to innovative treatments, and reimbursement of health care costs.**

Each patient organisation is unique in terms of the service offered, which in turn is influenced by the patient community they serve. This is reflected in the groups mission statement and objectives and whether they operate on a regional, national, or even international level. Some groups focus exclusively on voluntary work, while others employ professional staff. Irrespective of a group's profile, however, most patient organisations have two essential aims in common:

- To improve the situation of individual patients by providing information and support
- To improve the situation of patients in general through a commitment to patient-centred care, access to high quality treatment, promoting research, influencing health care policies, and advocating on behalf of their patient community.

At the very heart of any patient organisation's work is information. They make it possible for patients and their families to find out more about their cancer diagnosis by supplying them with information, or helping them access information from other organisations.

**"At the heart of any patient organisation's work is information"**

Patients or relatives usually make contact with patient organisations via websites, Facebook pages, online forums, or helplines. This is often followed by a telephone conversation or email, during which the patient or relative is given background information about their



disease, information about possible treatment options, or information about participation in clinical trials, depending on the needs of the patient. Some patients might get in touch with a patient organisation purely to make contact with others in the same situation as themselves, or for general support in their day-to-day lives.

Information is provided in a number of ways, such as online web pages, via forums and chat rooms, or in the form of leaflets or booklets, videos, newsletters, seminars, patient days, and much more: The aim is to provide a comprehensive range of up-to-date and objective information. The resources have generally been developed by the patient organisations themselves, by people who have first-hand experience of the disease, often in cooperation with leading cancer experts, to ensure the content is responsible, accurate and understandable.

**“The patient organisation’s role is to pass on what is the most up-to-date knowledge at the time – empowering patients to help themselves.”**

Usually, patient organisations are run by non-medics; by people who know and respect their own limitations. Because they are not professional clinicians or nurses, and are not party to the patient’s medical history, patient organisations are unable to recommend specific drugs or participation in particular clinical trials. However, they are able to

provide information about the latest medical advances, available treatment options, and relevant clinical research studies. If requested, some may also help the patient to arrange for a second opinion from a leading cancer specialist, but anything beyond that should be discussed by the patient with their medical team. The patient organisation’s role is to pass on the most up-to-date knowledge at the time – empowering patients to help themselves.

Patient organisations will often take on the role of advocates to help improve conditions for cancer patients. They work closely with key stakeholders in areas such as the quality of treatment, access to new & innovative therapies, reimbursement of treatment costs, and optimisation of research projects. Progress in the fight against cancer can only be brought about if patients, the medical and nursing community, research facilities, and other key stakeholders are involved and cooperating constructively with each other. We need to meet on a level playing field, respect each other, learn from each other and work as a team for the benefit of patients.

**“Medical research organisations, study groups and pharmaceutical companies are also increasingly involving experienced patient advocates in discussions about clinical trial strategy...”**

There are many excellent examples of patient and public involvement (PPI) initiatives and projects from around the world that have been made possible by collaborative working between patients, medical experts, pharmaceutical companies, hospitals, insurance companies, and health technology assessment (HTA) agencies. They include:

- Projects using patient focus groups to address care and treatment requirements
- Patient interviews aimed at uncovering issues, desires, and needs, with respect to treatment quality, quality of life and drug compliance
- Early access to innovative therapies and reimbursement of treatment costs
- Better management of therapies and their side effects, especially oral targeted therapies
- Cooperation in setting up and maintaining clinical registers
- Medical conferences, patient information days, and other training programmes.

## The Power of Patient Organisations

In recent years, pharmaceutical companies, hospitals, insurance companies and HTA agencies have increasingly involved patient organisations in advisory boards and committees:

- To create treatment guidelines
- To incorporate patient experience into guidelines and treatment advice
- To make better decisions relating to patient needs.

Patient advocates are also being included in discussions about clinical trial strategy with medical research organisations, study groups and pharmaceutical companies. Experienced patient advocates are involved early in the design phase of a clinical trial ensuring the opinions of patients are listened to, and their insight is used to improve trial design and ensure the trial closely reflects the use of the drug in real life situations.

**“In the past, much research failed to consult the patients themselves, despite being done for their benefit.”**

In the past, much research failed to consult the patients themselves, despite being done for their benefit. Future research needs to be carried out with input from patients to ensure the integrity of the research in the real world. A good example of PPI is AIDS/HIV research: What AIDS/HIV positive patients have achieved over the last 20 years in terms of being integrated into research-led projects is simply extraordinary. But how do patient organisations come to play an active part in research and clinical studies? There are essentially four areas that need to be covered:

### 1. Information on clinical studies and transparency

Patients tend not to be well informed about clinical trials. Unfortunately, there is still a misconception that doctors automatically inform their patients of all studies being carried out, or that patients actively search for clinical studies on websites, such as [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

Sometimes, medical experts and industry representatives notify patient organisations about upcoming clinical studies, so that they in turn can inform patients. Many groups publish information about clinical trials to inform patients and their doctors about particular studies. However, the research and medical terminology must be translated into a language that patients can easily understand. Some patient organisations also share study results – whether positive or negative – with patients.



### 2. Partner in research and study development

For optimal clinical trial design, researchers need to be aware of what it is like to live with a specific cancer diagnosis; patients need to be asked questions that are relevant for conducting the research, and defining study end points. The researchers need to determine what patients can realistically achieve in a clinical trial, and they need to make sure that patients understand exactly what is involved before they commit.

Patient organisations might not understand the overall drug development strategy and the reason for conducting some of the clinical trials, particularly when patients are given so little information about their existence. According to some studies, 49% of patients said lack of information was a reason why



they didn't participate in clinical studies. Equally inadequate is how study satisfaction is handled: Study participants are rarely asked about their experiences on clinical trials and feedback to help improve the design of future trials is, therefore, limited.

### 3. Generating additional evidence

Due to the rarity of certain forms of cancer and the low number of patients involved, it is particularly important to have access to as much additional evidence as possible. Well-managed patient organisations can help further research by providing relevant data and information from their own patient registries, or even by participating in the studies themselves. This can be done by means of questionnaires, surveys, interviews, case studies, video interviews, etc.

### 4. Being a catalyst, motivator and networker

Another role of a patient organisation is to bring together the appropriate experts, provide impetus, ask questions, motivate others, set-up and support networks, or kick-start bigger projects.

Some patient groups are already working in cooperation with hospitals and cancer centres. This is becoming ever more important, and appears to be a trend that the hospitals and cancer centres themselves are increasingly asking for. However, it is still rare to find a clinic or hospital that follows a genuine "patient-led strategy" and truly understands the need to essentially combine patients and self-help groups. Unfortunately, many countries still do not have enough cancer centres, which can afford to employ professional "patient relations experts" or to set up "patient boards" working closely and permanently with hospital management.

**The Book of Courage and Hope show cases the work of patient organisations from around the world. It highlights areas where these organisations have made a difference to the lives of kidney cancer patients and their families, be it through provision of information and support, information about clinical trials, help regarding access to treatment, or simply by including patients and family members in their valuable work, thereby giving them a new focus in life.**

**As health economies become ever more strained, the work of patient organisations becomes even more important for the care and support of our loved ones living with kidney cancer.**

*IKCC 2015 Conference brought together patient leaders from around the world*





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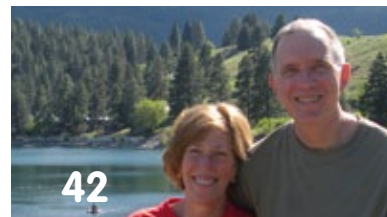
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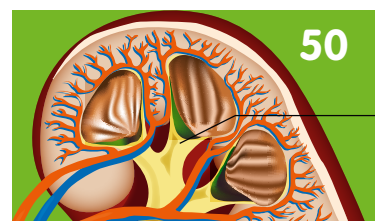
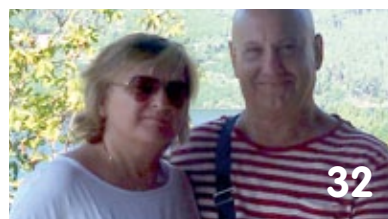
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Marnie and Matt Higgs' second child, Freddie, was an IVF baby. The Higgs had been through three exhausting transfers to fall pregnant before Freddie came along. He was a very welcomed and loved little baby. When their precious baby was only a few months old, Marnie found blood in his nappy. An ultrasound didn't reveal anything unusual; however, it was recommended that he have another scan when closer to 1 year old, as it looked like Freddie may have a double collecting system in his left kidney (a congenital abnormality). This was the start of Freddie's story ...

At 11 months old, Freddie had the check-up scan to look for this double collecting system in his left kidney; it wasn't there, but what the scan did show was terrifying: Freddie had a mass on his right kidney.

Marnie vaguely remembers being told that Freddie's GP was being contacted, and that they'd probably need to go to the hospital the next day. She wasn't really processing what was going on; it was all happening too quickly. He hadn't shown any symptoms.

Two days later Freddie had more scans, and the news wasn't good. He had a tumour. A room full of doctors told them they were unsure exactly what it was. There was a 95% chance it was a Wilm's tumour, 3% chance it was a different cancer, and 2% chance it was benign.

Just over a week after the initial scan, Freddie had a biopsy on his kidney under general anesthetic. There were even more people at the meeting to get the results than at the last one.

The Higgs were shocked when the oncologist said 'It wasn't what we were expecting'.

Freddie had kidney cancer.

It was rare and aggressive.

It was a one in 20 million diagnosis.

Marnie remembers babbling, crying, saying stuff that didn't make sense, like 'He's only a baby'. In books they talk about heaving sobs – that's what Marnie was doing. Wailing. It was four days before Freddie's first birthday.

Their baby boy had his kidney removed the next day.

They were able to see Freddie in recovery – he had wires everywhere and the machines were beeping. He looked like a peaceful little angel, and Marnie was finally able to hold him.

The cancer turned out to be a stage 3 renal cell carcinoma, which was horrifying. Freddie's oncologist said that the five-year survival rate for a child with stage 3 was 70%. All Marnie could think about was the one in three families whose child didn't live to see the five-year mark.

When they got home from the hospital, they tried to wrap their heads around everything that had happened in the past few weeks. They tried to keep things as normal as possible for both boys. But it was like how you feel when you have a holiday and your life is on pause, and then you have to go back to normal.

Freddie needs to have check-up CT chest or abdominal scans every three months, and his first post-surgery scan was pretty traumatic. It took five days to get the results – it was the longest wait. Everything rests on these quarterly scans. If there were any tumour growth, the prognosis would very quickly turn dire. It would mean the cancer had reached stage 4, and would mean more surgery and immunotherapy to prolong life. Every three months the Higgs literally hold their breath.

They have a dark sense of humour, which helps them through the hard times. Matt has Crohn's disease and is not always 100%. They are used to talking about health and medical procedures – outsiders may think 'that's so serious, how can you joke', but it's about making the other person laugh (to feel better), even though you're crying.

Every day is a Sunday for Freddie. He is a happy, cheeky, little man. He's got rolls in all the right places. He is hysterically funny and does things on purpose to get laughs. Apart from being one kidney down, Freddie's as normal as any other three year old now. Kids are amazing. They are resilient.

The cancer has helped them to cement their priorities and decide what to get upset over. 'It's not cancer' has become a bit of a motto.

There is still a dark cloud hanging over them, but they will get through it as a family. And they want everyone to know that Freddie is a survivor.

Their son is truly one in 20 million.



Kidney Health Australia is a national health care charity with a vision 'to save and improve the lives of Australians affected by kidney disease'. As the national peak body, Kidney Health Australia promotes good kidney health through delivery of programmes in education, advocacy, research and support.

Kidney Health Australia develops initiatives to save and improve the lives of Australians affected by kidney disease. We have given a long-term commitment to families and children affected by kidney disease, but the biggest challenge remains for us to reach the 1.7 million Australians who do not know they have early kidney damage.

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Instituto Oncoguia is a not-for-profit organisation created in 2009 with the purpose of helping cancer patients and the population to live better lives, developing programmes and initiatives on health promotion, disease prevention, wellness and patient rights. Promoting patient rights is a big part of what Instituto Oncoguia does through access to quality information, patient support and advocacy. Our multidisciplinary team works guided by the following goals:

**Maria de Fátima Oliveira is 53 years old, a broadcaster, married with two children, and several pets. She has always lived a busy life; full of work and family activities. However, she never failed to do her routine health checks and to take care of her nutrition. She always loved to look after the kids, to take care of the animals, and to give love and affection to everyone around her. The discovery of her cancer, as for many Brazilians, was slow, and the health professionals were inattentive and inexperienced with kidney cancer. Here is her story ...**

As soon as Maria de Fátima realised that her urine was darker than usual, she decided to go to her doctor believing it was just a urinary tract infection. She scheduled an appointment with her GP. During the wait for her appointment, her body started to give some more signals that something was wrong;

she lost weight, had strong cramps in her abdomen, nausea, severe fatigue, and bleeding when urinating.

The GP requested an ultrasound scan, found kidney stones in both kidneys, and started treatment with antibiotics. But the bleeding didn't stop, and continued more intensely. Maria de Fátima even had to be given a blood transfusion because of the heavy bleeding.

Time was passing; it was five months of intense pain and symptom aggravation, with no sign of improvement, until the doctor decided to refer her to a urologist. After another two months wait she eventually found a doctor who listened to her complaints, examined her and verified the examinations already done, checked the therapeutic measures used so far, and requested a CT scan of the urinary tract.



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- Offer quality information for patients, their families and the whole population.
- Educate the population and the patient about the importance of health self-care, wellness, quality of life and citizenship.
- Empower population and cancer patients giving them voice and offering support to their main needs.
- Increase citizens' participation on planning and monitoring of public policies.
- Promoting an active and responsible role that helps to improve cancer control.
- Promote and facilitate cancer patients' access to their rights.
- Contribute to the improvement of public policies related to cancer, engaging legislators and managers in the cause.
- Promote multidisciplinary action in health.

The results of this scan finally gave a diagnosis to all the symptoms that had been worsening, and over which Maria de Fátima had lost sleep: clear cell renal cell carcinoma, grade 1 (Fuhrman). 'Being told that you have cancer is already very difficult', she said 'but finding an insensitive doctor may be even worse'. The urologist had little experience dealing with situations like this and simply called her to the consulting room and said 'You must go immediately to the hospital, you need surgery to remove one of your kidneys'. Maria de Fátima was astonished, no reaction, just looking at the doctor. And the doctor, full of insensitivity, asked her 'Don't you understand? Yes, you have cancer!'

Maria de Fátima says that this was one of the most delicate and difficult moments of her life. She was alone in the clinic, without her family or a friend, no one around to help and give her strength. In her mind came her husband's image and, especially, the children. The doctor's words sounded like an imposed death sentence!

After absorbing and understanding the news, her main concern was to get informed as much as possible about the disease. The Oncoguia Institute Portal has become one of her most accessed pages; she said 'the constant conversations with the nursing staff, other patients and doctors who took care of pre-operative patients helped a lot also'.

A year ago, Maria de Fátima had one of her kidneys removed because of a 5.2 x 3.0 cm tumour. After surgery, scans were taken to check the recovery process and it was found that the tumour didn't extend to other organs. Therefore, the surgery was successful in removing all the tumour tissue and helping to control the disease.

Her oncologist has been fundamental during her treatment; after all the disappointments with the doctors who diagnosed her case, she has helped Maria a lot, being peaceful, caring, calm, and explaining and clarifying all her doubts with great clarity and delicacy. Maria de Fátima also belonged to a women's group for group therapy, sharing problems, listening to others, and praying. This strengthened her and helped her to face the situation. The women's group was a temporary measure, and now her life has returned back to normal.

Today, Maria de Fátima is fortified to continue taking care of her family and doing her job. She is a broadcaster with a radio programme in Rio Grande city, where she gives health and beauty advice. On the radio, she also advises listeners to check their bodies and to be alert to the signs and symptoms of their bodies. She remains very alert to her health, and has quarterly check-ups with her oncologist to confirm that there is no tumour recurrence.



**Andrew Weller knows the value of constant surveillance and expert care due to his participation in hereditary kidney cancer studies for over 30 years. Andrew's connection with kidney cancer began in 1972, when his father was diagnosed with the disease, resulting in a radical nephrectomy. His father remains active and is doing well in his retirement. One year after his father was diagnosed, his father's sister lost a kidney and then 2 years later lost her second kidney. After several years, she was fortunate to receive a donor kidney and lived for many more years. A year after his aunt's first nephrectomy, another one of his father's sisters lost both kidneys and eventually received two donor kidneys. She is now on home dialysis. This is Andrew's story ...**

With three of eight siblings having developed kidney cancer, the doctors started to compare the cases. After five siblings were diagnosed, everyone knew something was definitely going on and Andrew's extended family began being monitored. In those years monitoring was based on yearly ultrasound scans, which proved not to be particularly helpful in observing their tumours.

Around the same time there was a clinical study at the National Institutes of Health (NIH) in the US that later became the Von Hippel Lindau (VHL) study. The researchers were quick to enroll Andrew's family; however, doctors soon realised that, while something was clearly going on, the family didn't fit the mould for the VHL study. The NIH continued

to closely monitor Andrew's family, but they were 'put on the shelf' to wait for another study of hereditary types of kidney cancer.

With VHL identified, and other families starting to present with similar patterns of papillary renal cell carcinoma, doctors started to do studies with Andrew's family. Luckily the family was a big one – Andrew's father was one of 8 siblings, and Andrew has 27 first cousins. Rather than fly everyone down to the US, the researcher came to Canada to collect blood samples. The easiest way to do that was to invite the entire family over for a Thanksgiving dinner – except that all blood relatives first had to go into the kitchen to have blood drawn before they could eat or drink anything!

Almost 40 tubes of blood were collected, labelled, and flown back with the researcher to the US. Unfortunately, a mistake happened in the laboratory and the samples were mixed up, so the family had to have another 'blood-letting party' – this time at Christmas. Blood relatives again went first to the kitchen; in-laws were allowed to go into another room to celebrate.

Thanks to all of these efforts, the NIH was able to isolate the gene that causes Hereditary Papillary Renal Cell Carcinoma (HPRCC). The affected family members continue to visit the research centre regularly for close monitoring. Some of Andrew's cousins have also been on clinical trials for kidney-sparing surgeries and some have tested new medications. A carrier of the gene himself, Andrew has multiple bilateral cysts (on both kidneys) and has been monitoring their growth for the last 15 years. As an engineer by training, Andrew has tracked each of his scans and has predicted

exactly when he will need surgical intervention. In the meantime, he is considering clinical trials that might benefit him, his family, and other patients one day.

By coincidence, Andrew's cousin met a fellow Canadian, Deb Maskens, in a clinical waiting room and passed her contact details to Andrew. Andrew called Deb to volunteer with Kidney Cancer Canada. Andrew first became involved as a volunteer to redevelop the website, then on a survivorship committee, and then was elected to the Board.

Andrew is currently serving as the Chair of Kidney Cancer Canada. Andrew is a constant reminder that kidney cancer is not one

disease but many. He has two daughters who will one day be tested, but thanks to their father, their grandfather, and all of his family, their future with or without the gene looks very bright indeed.



### **Kidney Cancer Canada**

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Kidney Cancer Canada is a patient-led support organisation established in 2006 to improve the quality of life for Canadians living with kidney cancer.

Our goal is to help patients and caregivers navigate through the information they need to know about kidney cancer and its treatment and to increase awareness of kidney cancer as a significant health issue. We offer information, support, and advocacy to patients, caregivers, and family members and we work at many levels to improve access to quality care for all Canadians.

Kidney Cancer Canada has grown from 2 patients who met in a hospital waiting room into a vibrant and active community of over 2,000 supporters across Canada.

**Mercedes Bernal is the proud mother of two and grandmother of four. She doesn't like to sit around at home; she'd rather be driving round her home town Bogotá selling beauty products with her loving caregiver and husband, Lisímaco. Mercedes and Lisímaco do everything together; Lisímaco shadows her, making sure she is taken care of in whatever adventures each new day brings, even kidney cancer. This is her story ...**



Mercedes was diagnosed with kidney cancer in 2011. Cold-like symptoms and a sudden, acute pain in her abdomen, which reached her leg and wouldn't let her walk or even stand, made her husband and daughter rush Mercedes to the ER. A couple of weeks later she was diagnosed with locally advanced renal cell carcinoma, and was immediately ordered a radical nephrectomy of her left kidney. Mercedes was baffled by the news; wondering whether it was possible to live on one kidney. But she never gave up hope and her good humour. Neither did her husband. Three months after the diagnosis, the surgeon removed a one-pound tumour together with her left kidney.

Surgery was a success; however, complications didn't take long to appear. Her intestines were obstructed. The doctors had to open her up again to remove the obstruction. During the procedure she acquired a severe infection that kept her in bed on antibiotics for 20 days; even then, she would tease visitors mentioning how they were supposed to bring her a couple of beers!

Not too long after the nephrectomy, doctors discovered a tumour in her liver. This was certainly unexpected, but Mercedes and Lisímaco kept their heads up, giving support to one another through yet another cancer treatment process. Mercedes was treated with chemotherapy and, not surprisingly, came victorious out of this one, too.

Throughout the entire process, Mercedes' will to recover her health never failed her. Or she never failed her will. There were some rough patches along the way for sure, plenty of them, but that never dissuaded her in her fight. Neither did the obstacles wear out Lisímaco's determination to stay by his wife's side every single step of the way.

'I have never told him so...' Mercedes says, 'but I really admire him. People around us notice how much he cares. His support and the support from my kids and grandkids has been the source from where I find the strength to keep my head clear, my hopes high and my sense of humour intact. I am still the same; I was always the same, even when I was lying in bed at the hospital. If anything, the whole story fortified my faith. Now I am just looking forward to what is to come; my second granddaughter is on the way and it



will be me the one who takes cares of her, the same way I did before with my other three grandkids.'

Mercedes' recovery was something of a miracle; today she feels nothing but healthy and thankful. Whenever she gets the chance she recommends other cancer patients, without hesitation, to reach out to SIMMON for support. 'We were very lucky to find out about SIMMON shortly after Mercedes was diagnosed with kidney cancer' says Lisímaco. There are many cancer patients out there without any helping hand, people coming from remote places of the country who are not aware of their rights, or how to manage their disease.





To this day, Mercedes and Lisímaco keep driving up and down the streets of Bogotá delivering beauty products, going to check-up appointments, participating in activities for patients and caregivers at SIMMON, taking care of their grandkids, having fun – and a sip of beer or two – and simply enjoying life because, as she herself says ‘I’m not dead yet, I’m still alive, and you are supposed to make the most out of it while you can. Once you are dead, what sense does it make? Right?’



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**Website: [www.simmoncancer.org](http://www.simmoncancer.org)**

SIMMON is a non-profit organisation with nearly 7000 affiliated adult cancer patients in Colombia. SIMMON provides cancer patients, relatives and caregivers, counselling services free of charge in legal matters, psychology, nursing and nutrition; educating and empowering patients and community leaders on their rights and duties. SIMMON advocates for cancer patients’ rights before health authorities and decision makers in synergy with peer organisations at a national level and is partner in academic research projects that lead to a greater visibility of cancer patients’ needs associated to the health system and the improvement of their access to treatments with integrity, quality, dignity and opportunity. Through its year-round Promotion and Prevention Campaigns aimed at the general public, and conferences on early cancer detection and treatment for health professionals, SIMMON contributes to the national goals outlined in the National Cancer Control Plan to “Change the face of cancer”.



**Kinga Mathe is 46 years old, and married with one daughter. She is a lecturer in mathematics at a university in Germany. She was born in Romania and moved to Germany when she was 20. Kinga's story starts when her husband was offered a new job and the family moved back to Romania in September 2008 ...**

Kinga constantly felt tired and worn out. She blamed the stress of everyday life; she was working full time, her daughter was at a demanding age, her husband had a very stressful job, and she desperately tried to reconcile all of life's demands as perfectly as possible.

When her husband was offered a new job abroad, she saw this as a chance to slow down and renew her energies. So in September 2008, the family moved to Romania. For Kinga, it was like going home. The family settled in quickly, but Kinga still felt increasingly tired, although life had become a lot less stressful. After two 'bladder infections' with blood in her urine, a doctor friend referred her to have an ultrasound scan. It was the end of March, a wonderfully sunny day. And then the words of the doctor hit her like a lightning bolt: 'You have a big tumour in your right kidney and it is most likely to be cancer'. The day went instantly black. Her first thought was: 'This thing needs to come out as soon as possible'. And she was lucky to get surgery just three days later by one of the best specialists in Romania.

She was discharged as 'cured' but advised to have regular check-ups. Everything happened so quickly that she didn't have the opportunity to become informed or ask questions

before the operation. Once the pathology report arrived she wanted to understand and began to read up. Her tumour was stage T3a, not good news, and the more she read, the more she got a 'feel' for her illness. She quickly understood that at such a late stage of being diagnosed chances were high for it to return at any given time, and she wanted to be prepared. She started to gather as much information as possible and very soon came across Das Lebenshaus, a German patient organisation that supports patients with kidney cancer.

In September 2010, the family returned to Germany and Kinga went back to work. She made contact with Das Lebenshaus and instantly felt accepted and understood. In April 2011, she attended her first patient information event, where she got to know the best kidney cancer specialists, and met others who shared her illness. Some of these people she affectionately calls her 'kidney cancer family'. She received so much help and gained so much hope that she felt the need to give something back, and decided to start a local patient group in Stuttgart in 2013.

After a wonderful holiday she came back in time for her annual MRI scan. She was relaxed and felt fit and healthy. She had to wait

unusually long to see the doctor afterwards - she knew: the cancer had returned! She received the report the next day and the radiologist mentioned two large metastases in the pancreas.

She contacted one of the kidney cancer specialists and he arranged for a further scan, which disclosed at least four more metastases in the pancreas. However, he also confirmed that the cancer had not spread any further. He discussed in depth all the available therapies, including the advantages, weaknesses and expected consequences of each. She decided to try immunotherapy. Unfortunately, immunotherapy wasn't successful, and she has now been on targeted therapy for over a year. She responds very well to this therapy, and only 2 of the 6 pancreatic metastases remain visible on CT, and these have also considerably decreased in size. The side effects are strong, but she has organised her life in a way that she can live well despite them.

She has stopped working, and continues with a healthy lifestyle, exercising whenever treatment allows. During therapy breaks, she travels the world and hopes to see a lot more. Every year on her daughter's birthday she says to herself: 'I have managed to live for another year!' She can still see the fear in the eyes of



her then eight-year-old daughter and her own despair and fear of not seeing her grow up. Her little girl has now grown into a beautiful young woman, becoming more and more independent. She cannot express her gratitude in words!

Kinga continues to actively engage with Das Lebenshaus as a member of the board. This gives her strength and confidence. She is tough and intends to live for a long time with this disease, since it is worth it: Life and living are wonderful!



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**Website: [www.lh-nierenkrebs.org](http://www.lh-nierenkrebs.org)**

Das Lebenshaus e.V./Assoc. is a non-profit umbrella organisation for those affected by rare solid tumors: kidney cancer, GIST and sarcoma. From the start, the organisation's philosophy has been to work professionally with medical experts, researchers, the pharmaceutical industry and other patient organisations around the world to achieve the best possible outcome for those affected.

We design, organise and implement all measures and activities in cooperation with kidney cancer patients, their caregivers and a Medical Scientific Advisory Board. Our interest in kidney cancer propels us to raise awareness so that people in need are connected to resources when they exist, and that attention is drawn to highlight service gaps when services to improve quality of life are absent.

Besides the support of patients we are also active on many other levels e.g. representing the patient perspective in the German RCC guidelines.



**Dipankar Bhattacharjee lives with his wife and son in Mumbai, India. He was diagnosed with kidney cancer during a trip to Kolkata in 2009. After surgery in September 2009, the cancer returned the following year. This is Dipankar's story ...**

The memories of that day are still etched in Dipankar's memory like it was yesterday. This was a time during one of the family's trips to Kolkata. Unfortunately, Dipankar had been feeling low for quite a few days. He had been running a fever, and his family were quite worried, given that swine flu had wreaked havoc in India and had left the health authorities feeling hapless. However, they were not prepared for what the trip to the local doctor was to reveal. Seated inside a very homely looking drawing room turned clinic, Dipankar and his wife had steeled themselves for the worst-case scenario; swine flu. But little did they know that their world was going to be turned upside down. The doctor's furrowed brows had warned them that the news was not good. The moment the words 'You have cancer' came out of his mouth, Dipankar seemed to zone out. The first thought to pop up in his mind was 'How could I have a tumour in my kidney?' It was gut wrenching! His mind was racing ... his thoughts too fast to comprehend...thinking about what could have gone wrong. Although his wife thought he took the news very well, he was in turmoil inside and no words can describe how he felt.

Dipankar and his wife returned to Mumbai on the earliest flight under the ruse that he had an infection and needed to consult a doctor in Mumbai. They did not want the news that he had cancer to get out, because they did not want to believe it themselves. But after doing the rounds of many doctors and several second opinions later, they finally came to terms with the diagnosis and it was time to look ahead. By this time, Dipankar had become numb to the shock after having heard the diagnosis a number of times. The word 'cancer' did not hold as great a fear as it did earlier. For this, Dipankar thanks his doctor; once cancer is viewed objectively, Dipankar realised that cancer was a hurdle like any other in his life. And hurdles can be overcome!

Dipankar was operated on in September 2009 in one of the premier hospitals in Mumbai by one of the best surgeons, and probably one of the kindest and most cheerful people that he has ever met. He remained disease free till March 2010, when the cancer returned. He was diagnosed with metastases in his lungs and ribs. His doctor had warned him about the possibility of metastases during his surgery. Hence, this did not seem as big a blow. But he had a new battle to fight, for which he needed a new weapon (chemotherapy) and another doctor. He is extremely thankful to have been in the care of a wonderful medical oncologist. He started his

battle with chemotherapy and has been fighting ever since. It has been a tough six years for Dipankar and his family; they have had to watch him fight the cancer from the sidelines, without being able to do much about it. His wife and son have made many sacrifices; too many to put into words. Finally, his journey would not have been what it is without the unconditional and heartwarming support that he received from his work colleagues in Mumbai.

Dipankar still feels tired, but he is only human. However, this is his life and life is beautiful and worth fighting for. The bottom line is that, although he has cancer, he is still alive and kicking and happy. His message to any newly diagnosed cancer patients reading this is to 'listen to your doctor and do not give up. Cancer is not the end of the road. The road ends when and where you want it to. Your life is still yours and within your grasp. Live it and live it to the fullest.'





**V Care Foundation**  
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**Website: [www.vcarecancer.org](http://www.vcarecancer.org)**

V Care Foundation is a voluntary support group dedicated to providing free help, hope, awareness and education to cancer patients and their families through outreach programmes and services that improve the quality of their lives.

Honorary volunteers group is a distinguishing strength; it consists of either cancer survivors and those who had some experience in helping cancer patients, or those who have empathy for those who suffer and with high sense of commitment and

passion. They are not paid volunteers; in fact, they pay V Care Foundation a small amount of annual subscription.

A group of volunteers form the backbone of the foundation, which interacts with patients, gives ideas for extending service and support to cancer patients; it keeps the foundation ticking.

Various events are organised to spread messages of happiness and better quality of life after cancer. Patients get an opportunity to interact with doctors, caregivers, volunteers and survivors.



**Ait Zaouit Mohamed was born and lives in Casablanca, Morocco's capital city, with his wife and two children. He has led a quiet and healthy life as a taxi driver, and doesn't have any bad habits, such as smoking or drinking alcohol. As a result, he never had the need for hospital treatment, until 2006. After suffering intensive back pain on his left side, Ait Zaouit Mohamed was persuaded by his mother to see a doctor. This is his story ...**

Ait Zaouit Mohamed was born in 1970 in Casablanca, the largest city in Morocco and the country's economic centre. He has led a quiet and tidy life as a taxi driver since 1997.

It all started in March 2006, when he suddenly had intensive back pain on his left side after having eaten some food. He'd never been to hospital before. At first, he refused to see a doctor thinking that the pain would go in no time. But when his mother insisted on the fact, he took her advice and went to a nearby doctor. After the examination, the general physician told him that he had a kidney stone and he was prescribed some medicines, which he purchased from the pharmacist and went home to have some rest.

However, that same day in the afternoon, the pain returned and he was obliged to go immediately to the University Hospital Center in Casablanca, where his sister worked as a nurse. After the abdominal scan, it was clear that the source of the pain was an 8 cm tumour in his left kidney.

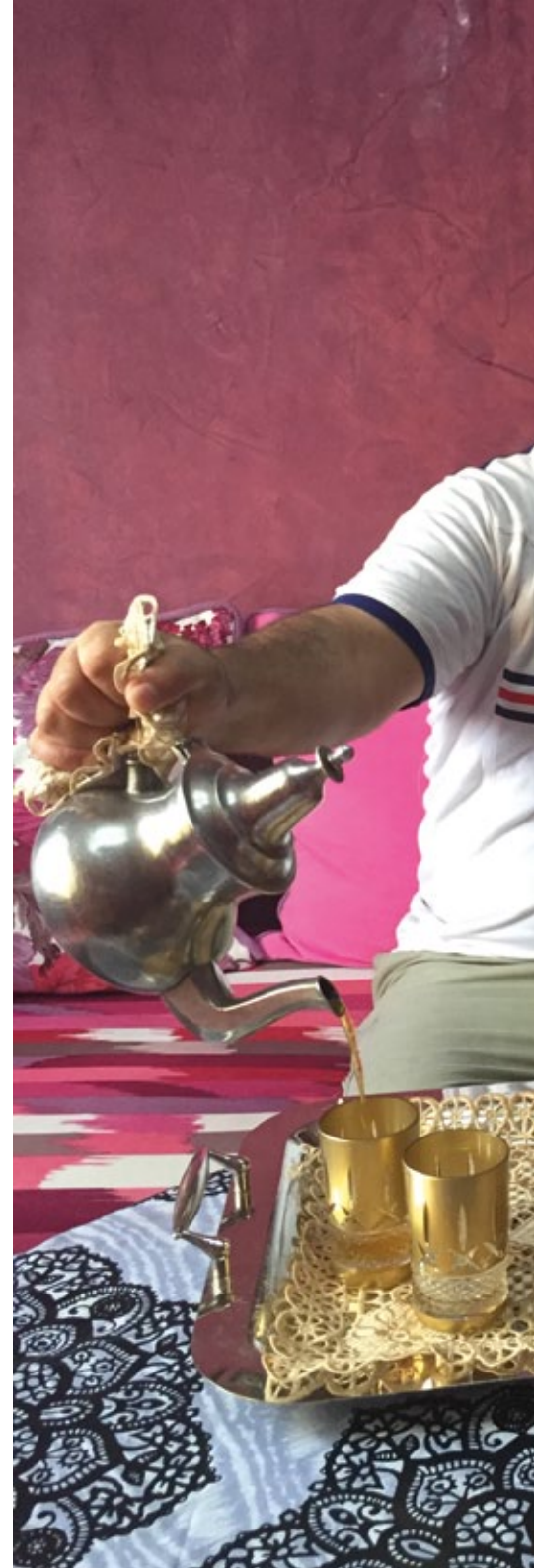
He was really stunned, because the symptoms he had were not indicative of such a life-threatening illness. Many dark thoughts crossed his lost mind. Would he see his

dreams in life come true (he longed to get married and have children), or would he pass away before his dreams could be realised? He had recently got engaged to the girl his heart had chosen.

The urologist told him that he needed a radical nephrectomy, but did not explain further. This was done within a couple of days, and at the same time physical and pathological examinations were performed. Thankfully, the operation was a success. Three months later, he underwent 6 weeks of radiotherapy (25 sessions). It was not an easy time, since he had to deal with nausea after each session. At that time, he lost a lot of weight and became anorexic.

In the hospital waiting room, Ait Zaouit Mohamed met a lot of cancer patients but he did not engage in conversation with them, or build relationships with them. He is shy by nature and it seemed to him that each patient was struggling and suffering alone.

Ait Zaouit Mohamed didn't have any medical insurance, and his family, especially his father, supported all his hospital expenses. In total, his medical care and treatment cost approximately 60,000 Moroccan Dirhams (6,000 US Dollars).







After the radiotherapy sessions, he felt better. He had no more digestive disorders and regained his appetite and weight.

The most comforting aspect of Ait Zaouit Mohamed's difficult experience was that throughout this period, he really appreciated the psychological support from his whole family, neighbours and friends. It helped him a lot to cope with the disease, gave him self-confidence, and enhanced his faith in God and the pleasure of life.

At last, Ait Zaouit Mohamed's terrible nightmare was over, and he got married on October 20th, 2006. He now has two lovely children, born in September 2012 and April 2015. He is grateful to his wife, who still supports him.

He considers himself a kidney cancer survivor. Now, he lives a normal life with his little family and continues to have medical checkups once a year.

He learned from this experience how important faith and support is for keeping his spirits up and for a quick recovery.

His message to other kidney cancer patients is: 'Believe that recovery is possible, mainly if diagnosis is done early. Keep faith and hope. You will always find people around praying for you'.

He hopes that doctors will become more aware of kidney cancer, and will take the time to explain all the alternative therapies to their patients; this will reduce anxiety and help them cope better with their illness. He also wishes that patients can find and gather in associations, which can help them through the provision of information and advocacy. The ultimate goal would be better quality of care for better survival.

الفيدرالية المغربية لجمعيات مساعدة  
مرضى الفصور الكلوي وزرع الأعضاء  
Fédération Marocaine des Associations de Soutien  
des Insuffisants Rénaux et de Transplantation d'Organes



F.M.A.I.R.T.O

**Moroccan Federation of Associations  
supporting patients with CKD and  
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FMAIRTO was created in Rabat in June 2005 in order to help regional associations

to better organise, ensure adequate training to their members and build partnerships with the Moroccan ministry of health and other national and international associations.

The goal of our association is to support patients with renal failure by listening to their concerns, informing them about kidney disease, renal failure, dialysis and kidney transplantation, and encouraging people to donate organs.

In April 2015, we joined the IKCC and extended our activities to people suffering from kidney cancer. We aim to raise awareness about kidney cancer and advocate for better care and support for patients.



**Wim van Beek was enjoying a successful career as a team manager, and attending college courses in his free time to obtain another degree in his hometown of Prinsenbeek, The Netherlands, when on April 14th 2014, everything changed. Initially, he was told he had a bladder infection and was prescribed antibiotics. It wasn't until he sought the opinion of a second family doctor that he was given a referral to see a urologist. Here is Wim's story ...**

Wim had pain in his side, and when blood appeared in his urine, he went to see his family doctor. A bladder infection, he was told. Take antibiotics and it will get better, he was told. Two days later he urinated even more blood, but his doctor just changed the antibiotic prescription. Nothing improved, so Wim asked to see another family practitioner at his local clinic; this one made an appointment for him with the urologist and sent him to the hospital for imaging. Wim was feeling normal again - all his complaints had disappeared - when he heard one month later that he had a large tumour in his right kidney, too difficult to remove surgically because two lymph nodes were also affected by the cancer and they were positioned against the renal artery.

Wim was sent to a hospital specialising in cancer in Amsterdam, 1.5 hours drive from his home. There he spoke with a medical oncologist and his treating urologist, who told Wim that he had clear cell carcinoma of the kidney and that he would need to take pazopanib before they could operate to remove the

tumour and the affected lymph nodes. Although he suffered liver problems as a result of the treatment, Wim's tumour and nodes shrank in response to the pazopanib. After a break of 10 days, Wim's liver recovered, and Wim and his medical team decided to re-start pazopanib at a lower dose, which they were able to raise incrementally. In October the urologist performed a radical nephrectomy on his right kidney, as well as removing the right adrenal gland and local lymph nodes. After 3 months recovering from the surgery, Wim started working half-days. He regained the strength he had lost during the previous month and felt well on the road to recovery.

Four months later, a routine scan showed a single tumour in his right lung and a suspected spot in his left lung; the kidney cancer had metastasised. The doctors decided to treat Wim's lung tumour with radiofrequency ablation and burned over 9 cm of lung tissue. The next day, Wim felt well and went home. However, later in the afternoon that day he had remarkable pain and had to return to the hospital by ambulance, where he spent over a week in the hospital while his damaged lung recovered from an acquired post-surgery pneumonia, which returned 3 weeks later.

Wim and his wife regularly had to navigate his own care; for example, they had to challenge his prescription for pain medication when the attending physician had not taken into account that Wim only had one kidney. The complications surrounding the lung treatment lasted months and sent him between local hospitals and the cancer centre in Amsterdam, seeking help and information from a variety of sources. A suspected spot in his left lung found at his local hospital turned out to be just a scar when the cancer centre in Amsterdam re-examined him.

Wim has been back on his feet for several months now, working part time and is currently cancer free. Eager to put this difficult year behind them, Wim and his wife are taking a vacation. Wim acknowledges that he received amazing support from his wife, family, and friends during this journey, online support for information, and that his employer was exemplary in their support and flexibility with regard to his need for time off work. Wim now has the opportunity to finish that degree!





**Living with Bladder or Kidney Cancer  
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Website: [www.kanker.nl/organisaties/levenmetblaas-of-nierkanker](http://www.kanker.nl/organisaties/levenmetblaas-of-nierkanker)**

Living with Bladder or Kidney Cancer is the Dutch support organisation representing people affected by all urological cancers. We are run entirely by volunteers, and serve nearly 1000 patients with kidney cancer. We are supported by annual grants from the Dutch Cancer Society as well as the Dutch Ministry of Health in addition to private donations and membership fees.

Hearing that you have kidney cancer is an extremely intimidating experience, and ushers in a time of uncertainty and questions for the patient. We provide a network to guide patients and their families through this process. We bring people together to exchange experiences, fears, anxieties, grief, as well as practical advice on dealing with pain, exhaustion, insurance, relationships, and income.



**The Association of patients with prostate and urinary tract diseases**

**Association "GLADIATOR"**

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**Marian Ornat is 62 and works as a technical and investment manager in the research and development institute in Lodz, Poland. He is married with two adult children. Without the support of his family, and particularly his wife Beata, he would not have survived the past four years since his diagnosis of cancer. This is his story ...**

The diagnosis of kidney cancer was like a bolt out of the blue for Marian and his family. He used to be a very active person; devoting most of his time to work, and was never seriously ill. He never thought he would succumb to cancer. None of his immediate family has ever had cancer and his professional work never exposed him to carcinogens. Many times he has asked himself and the doctors: Why me? He doesn't smoke, or abuse alcohol.

He follows a healthy diet and is physically active. However, he still doesn't know the cause of his cancer. Regular medical check-ups and being aware of abnormal signals from our bodies help to detect cancer; the earlier cancer is diagnosed, the better the chances for a complete recovery.

The diagnosis of kidney cancer came quite accidentally. It was without any symptoms for a long time. The first symptoms were lumbar pains and frequent urination, often at night. At first Marian thought the symptoms were as a result of driving the car or his age. His first visit to the urologist did not bring an answer to his symptoms; he was examined and prescribed antibiotics, which only intensified his symptoms. He consulted a different doctor, who performed an abdominal ultrasound scan. Marian was diagnosed with clear cell renal cell carcinoma, stage pT3b, and Fuhrman grade 2. The diagnosis was like a death sentence, although the doctor did his best to inform him about it in the most quiet and composed way: '... the prostate is normal in your case. Unfortunately, in your left kidney



The Gladiator Association for men with cancer diseases of the prostate, kidney, bladder and urinary tract is a non-profit organisation.

Our activity aim is unification of our patient members and education in the direction of the basic medicine rules to assure early detection and correct diagnosis and the necessity of prevention testing.

there is a tumour about 8 cm in diameter. The only help is the soonest possible nephrectomy of the left kidney.'

Three days later, a CT scan of abdominal cavity and lungs confirmed the cancer was in the left kidney and other organs were clear. The nephrectomy was successfully carried out 2 weeks later in August 2011. The doctor informed Marian that you can never be sure that all the cancer cells have been removed, leaving some to spread to other organs later on. Yet, at that time the nephrectomy was the light in the tunnel, and a return to life.

The words of his surgeon were confirmed 3 months later when, during a routine check-up, three metastases were found in his left lung. These were surgically removed in

January 2012; however, further metastases were found in the right lung for which Marian had targeted therapy funded by the Polish National Health Fund.

He was treated with sunitinib until September 2012 when it was confirmed that the lung metastases had progressed. Second line treatment was everolimus, which he took from September 2012 until April 2015. All that time the disease was stable and he tolerated everolimus much better than sunitinib (he had hand-foot syndrome when on sunitinib).

Unfortunately, in April 2015 his disease progressed and he had exhausted the standard treatment available in Poland and reimbursed by the National Health Fund. Marian was left with his disease and without any anticancer medicine, and was unable to pay for private treatment. It seemed like he was fighting a losing battle, but he was determined not to give up. During his next visit to the doctor, she suggested trying another medicine – axitinib another second line treatment that is reimbursed by the National Health Fund. However, it is not reimbursed as a third line treatment. Thanks to the help of his doctor and the Pfizer representative in Poland he was lucky to be given axitinib for two months. The CT scan after 2 months indicated stability and that axitinib fights his cancer.

Marian is now fighting for third line treatment with axitinib from the National Health Fund, with the support of the Gladiator Association and other kind-hearted people. He has not taken any anticancer drugs for over 2 months and he hopes he will manage without the cancer progressing until he can access axitinib again. For the time being, he is trying to strengthen his immune system with herbal remedies, such as turmeric, milk thistle, garlic, rockrose, linseed oil, and apricot seed oil. He is still alive and fighting for further life; deep in his heart he is an optimist.







**Rui Carvalho is 41 years old and married with a young son. He lives in Portugal with his family and works for a multinational financial group. In the summer of 2014, Rui celebrated his 40th birthday with a wonderful trip to Italy. However, since the beginning of the summer he was bothered by a light 'pinch' on the right side of his abdomen. He kept thinking that he should get it checked out by the doctor, so after the summer he made an appointment. This was the start of Rui's story ...**

One of the things in life Rui was most afraid of was the word 'cancer' and what it meant. However, unknowingly, cancer suddenly came into his life. When the hard reality hit him, he didn't want to believe it: It felt like a big nightmare that he wanted to wake up from.

It was mid-September when Rui finally decided to go and see the doctor. The doctor referred him for some liver and gall bladder examinations, and an abdominal ultrasound. At the ultrasound, the radiologist said, "Your liver and gall bladder are just fine", to which Rui immediately replied "Great!" But then the radiologist added "But you have a lump in your right kidney." Rui didn't even know what that was, but he went back to his family doctor, who then started to suspect something more serious. Rui repeated the ultrasound scan and also had a CT scan but, unfortunately, both tests came back with the same results. After a few consultations, there was no doubt; the doctors didn't even consider a biopsy and decided to go ahead with the surgery right away.

As ironic as life can be, Rui's father is a retired urology nurse, and he had worked in the same hospital unit where Rui was going to have surgery. That was when Rui finally realised what was going on. He was going to have surgery to remove a kidney tumour, with a high chance of it being malignant. During the days leading up to surgery Rui was extremely anxious. He looked at his son and wanted to cry; he kept thinking he wouldn't live to see his son grow up. He wandered around the house and didn't talk much; his only thoughts were on the surgery. His work was the only thing that helped him forget and come out of the deep sadness that he was feeling.

When Rui was finally admitted for surgery, that night alone in the hospital was one of the hardest in his life. He was very frightened and he prayed for everything to be okay. When he woke up from surgery, the first words he heard indicated that everything had gone well. He remained in the hospital for a week, where he stayed with two very nice gentlemen that he will never forget.



After 2 weeks, the results of the pathology report came back: Rui had clear cell renal carcinoma, grade 2 (Fuhrman). The wonderful doctor who did the surgery said that he was theoretically cured, and it was time to move on. It's been a year since the surgery and now Rui has urology appointments every 6 months.

Rui has a degree in marketing and has worked for a multinational financial group since 2007 as a Commercial Manager. His hobbies include cycling and motorcycling, and listening to music. He likes to travel; he loves to eat and cook, and to be with friends.





**Associação Portuguesa de Insuficientes Renais (APIR)**  
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APIR is a patient-led support organisation established in 1978 to improve the quality of life for Portuguese kidney disease patients. In 2014, APIR created a new section to support Portuguese patients living with kidney cancer.

Our goal is to help patients and caregivers navigate through the information they need to know about kidney cancer and its treatment, and to increase awareness of kidney cancer as a significant health issue.

We offer information, support, and advocacy to patients, caregivers, and family members, and we work at many levels to improve access to quality care.

APIR has about 3,000 members and the Kidney Cancer section is a growing one. We soon hope to have a group of advocates who will be able to support and assist kidney cancer patients around the country.

Today he knows that he is a more considerate person than he used to be, but also with renewed zest for life. The verbs that move him now are 'to go', 'to do', 'to try', 'to taste'. He tries to do today what he may not be able to do tomorrow. He is now 41 years old, and married with a 6-year-old son, who makes it all worthwhile.

He used to make long-term plans, but now he tries to live life to the fullest, and with the people he loves. He hopes the future allows him to see his son grow up, and he believes it will!

Rui would like to thank all the great health professionals that have been there for him during his journey, especially when he was in the hospital. And he would like to thank his family, especially his parents, for all their help and support during this difficult period of his life.





The Cancer Association of South Africa (CANSA) enables research, educates the public and provides support to all people affected by cancer. As a leading role-player in cancer research, the scientific findings and knowledge gained from our research are used to realign our health programmes as well as strengthen our watchdog role to the greater benefit of the public. CANSA offers health awareness cancer screening and education campaigns,

**Mark Walter is 66 years old and lives in Amanzimtoti, South Africa with his wife, Odette, the most important person in his journey. The Walters have 3 children and 5 grandchildren. When facing a diagnosis of cancer, Mark recommends that a strong faith, strong partner, and a strong family unit are needed, as well as a positive attitude. Please read Mark's story...**

Mark's journey started on 9th February 2011; whilst undergoing a routine check-up his urologist felt a lump in his right kidney. A CT scan found a 5.2 cm dense mass, the density indicating malignancy. Mark was diagnosed with kidney cancer and was scheduled to have his kidney removed. His mind took control and all things faded into oblivion as to where else the cancer could be in his body.

He had his kidney removed, returned home, got stronger, and went back to work. He and his wife also started travelling more around South Africa, Mark being an avid wildlife photographer.

At his next two annual check-ups, Mark was given the 'all clear'. However, in January 2014 he had an abdominal scan and chest X-ray, which showed multiple lesions in the upper

lobes of his lungs, highly suggestive of pulmonary metastases. A further chest CT scan confirmed multiple metastases in the lungs and an enlarged lymph node.

Mark had been retired for less than a year, travelling for several months, feeling really well, relaxed, and with no sign of any problem whatsoever – the questions were 'What now?' and 'Were the doctors correct?'.

Immediately Mark saw the oncologist, who assured him that, with medications available today the cancer is controllable; however, a biopsy was needed. The biopsy proved inconclusive. In February 2014 he had a thoracotomy, and kidney cancer was confirmed. This was a hectic operation with lots of pain. Mark's recovery was slow and painful, as a rib was broken during the operation.

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30 CANSA Care Centres that offer a wide range of care and support services to those affected by cancer, offer stoma and other clinical support and organisational management, medical equipment hire as well as a toll-free line to offer information and support.

We also supply patient care and support in the form of 11 CANSA Care Homes in the main metropolitan areas for out-of-town cancer patients plus one hospitium based in

Polokwane, as well as CANSA-TLC lodging and support for parents and guardians of children undergoing cancer treatment.

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Twitter, Facebook, Instagram, YouTube and  
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Later that month he was put on sunitinib; this was an anxious time as he waited for sunitinib to work. The sunitinib affected his thyroid function, but in June 2014 a CT scan showed a reduction in the number of metastases, suggesting improvement. However, a rib lesion was noted, which he was never informed about after the operation in February.

A CT scan in October 2014 showed only one nodule in the left upper lobe, which had not changed from last 2 scans. The lymph node had also shrunk in size. This was cycle number 6 on sunitinib and everything was looking good; Mark was feeling very positive, so decided to have a break from sunitinib for 3 months to recover from the side effects.

In January 2015, a CT scan showed stable disease and further reduction in the size of the lymph node. There was no evidence of new metastases. This was great news overall, since Mark and his wife wanted to do more travelling.

Whilst travelling during February and March 2015, Mark felt a dull pain in his ribs, just under his left breast. This pain got very intense at times and on occasions he couldn't sleep. However, a CT scan showed stable disease and a further reduction in the lymph node. But Mark was still concerned about the pain in his ribs. His oncologist read the report, examined him, then looked at the scans. Immediately he called the radiologist, since there was a 50 mm lesion on Mark's spine, which was causing the pain. Mark had been misdiagnosed by the radiologist.

Within 2 days he saw the best neurosurgeon during his hospital rounds, and was immediately admitted. He needed urgent surgery as the tumour could cause paralysis if not attended to. Mark underwent a 5 hour operation where 90% of the tumour was removed and was told he would need radiotherapy to assist in killing the tumour. Two weeks after surgery Mark had 10 daily sessions of radiotherapy.

In May/June 2015, Mark commenced treatment with sorafenib and his latest CT scan showed that the lesion on the spine was exactly the same size as when the radiotherapy was given, so the sorafenib is working.

Mark continues to take sorafenib, food supplements and lots of water. Assisted by his wife, he is sure a healthy diet has contributed to far better management of his treatment.

Mark's sincere appreciation goes to his wife, Odette, who has stood by him every step of the way; he remembers so clearly her saying in the beginning 'We will handle this together'.

Finally it is very important to note that after all Mark has been through he has never asked 'Why me?' His strong faith in God has taken care of him.

**Jose Luis Garcia is a Spanish entrepreneur who ran his own business, an auto repair shop, until he had to retire due to illness. He is married and has two children, and lives in the Spanish region of La Coruna. In 2008, during a routine medical examination, some abnormalities were detected in his blood. After several tests and reviews, kidney cancer was diagnosed. Although this disease has an important genetic and hereditary component, José Luis didn't know of anyone in his family who had kidney cancer; this confounded his stress and anguish. Please read Jose Luis' story ...**



After a period of consultations and medical opinions, the doctors removed the affected kidney. After the operation and subsequent treatment, José Luis had to stop working; he was declared unfit for work. Although he still owns the auto repair shop, he no longer works directly as a mechanic, and has hired professionals to take over the responsibility for running the business.

Later, by chance he met the president of the Associations for the Fight Against Kidney Disease (ALCER) in La Coruna (ALCER Coruna), the Spanish region where he lives. The president of ALCER Coruna was one of his clients, and they soon became friends.

When he had recovered from the disease and adapted to the new situation, he received more bad news during a follow-up assessment in 2013. The doctors confirmed that the evidence suggested metastatic kidney cancer, in addition to a Burkitt lymphoma; a rare type of non-Hodgkin's lymphoma, cancer of the lymphatic system. He had further tests and surgery to remove the tumour, followed by chemotherapy after his surgery.

Today, Jose Luis is fully recovered and in good general physical condition. After surgery, he was left with reduced kidney function, and he is now forced to take adequate care of his remaining healthy kidney and follow good renal health habits.

In May 2015, his friend, the president of ALCER Coruna and member of the National Federation of ALCER, asked Jose Luis to lead a group of kidney cancer patients within the ALCER Federation. Jose Luis did not hesitate and accepted the proposal, offering his help to the Federation for whatever was necessary. The group is responsible for emotional support and counselling of patients with kidney cancer in Spain within the National Federation of ALCER.





**ALCER**  
Federación Nacional

**National Federation of Associations  
for the Fight Against Kidney Disease  
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ALCER is the Spanish Federation of Associations for the Fight Against Kidney Disease, including kidney cancer. It is a patient-led support organisation, established in 1976 to improve the quality of life for Spanish people living with kidney disease.

The Group of Kidney Cancer Patients of ALCER share experiences, testimonies, information and all they need to face kidney cancer. Also, we provide our kidney cancer group the common services of our Federation, such as psycho-social support, advocacy to patients, relations with medical societies and other cancer patient organisations in order to offer the latest updates about investigations and treatments.

ALCER today has nearly 19,000 members, most of them patients. The kidney cancer group was created in 2015, but we began to work in kidney cancer in 2006.



**Christy Watson lives with her husband and two young sons in Prestwick, Scotland. After travelling with her husband's job for 10 years the family moved back to Christy's hometown of Prestwick 6 years ago. She wanted her family to grow up in this beautiful part of the world, and it was lovely to have her old friends and family just 'down the road'. However, she didn't quite realise how much she would need them in future months ...**

Christy had her son, Rory, in Poland and not long after moving back to Scotland her and her husband decided to have a second child. Her pregnancy wasn't easy; she was constantly tired and had multiple colds, sinusitis and tonsillitis. She put it down to a tough pregnancy and the added effort of looking after a toddler.

When their second son, Jay, was born they were absolutely delighted, but Christy was told she had Streptococcus B infection, which, unfortunately, Jay had contracted. It was touch and go for Jay, but after being treated for meningitis he slowly started to respond and get better. Christy was then diagnosed with a womb infection. She had no idea how much strain her immune system was under, and what her body was actually dealing with.

When Jay was about 10 weeks old, Christy went back to her doctor, as her body hadn't settled down since Jay's birth. She thought it was possibly to do with the womb infection, so she went for an ultrasound. She was assured her womb looked fine. Just as she was leaving the room the nurse asked if she had ever had tests done on her kidneys; she said 'no' but immediately alarm bells started ringing.



Her doctor called her the next day to say she was booked in for a CT scan, but she shouldn't worry because at her age it would either be a cyst or a shadow. How wrong she was. That scan showed a 7cm clear cell renal tumour on her right kidney, and she was scheduled for a radical nephrectomy in 2 weeks time.

At the diagnosis stage, there was the feeling of disbelief, shock, panic, confusion, lack of control, bewilderment and anger. Christy was only 36 years old with a 2 ½ year-old son and a 3 month-old baby. She couldn't let them see or feel her fear. One of the hardest things to deal with was telling her family and close friends.

Christy was fortunate that she had keyhole surgery and a very good surgeon. She didn't enjoy her time in hospital, though; she felt very lonely and was desperate to be with her family. She was forced to stop breast-feeding because of the surgery, and Jay was very reluctant to take formula from a bottle. It was a very stressful and upsetting time.

The cancer was aggressive, and Christy was told there was a high chance it would come back; she met the criteria to go on the SORCE trial. It was mentally and physically tough, but allowed Christy to be proactive and give others hope for the future of renal cancer treatments.

Christy attended the cancer hospital in Glasgow, where her specialist research nurse was a great support throughout the 3-year clinical trial. She was fully informed about what lay ahead in terms of side effects and how the trial would proceed. By the 10th month, the

side effects were badly affecting her quality of life; she had terribly sore feet, lost all her body hair, had painful skin sores, rashes, and couldn't stray too far from a loo! The fatigue was tough, especially with 2 pre-schoolers at home all day! She was lucky to have the nurse at the end of the phone or on email, and her mum and sister minutes away to rescue her if it was a really bad day.

Initially, to give her and her family something to focus on rather than the cancer, they started fundraising for kidney cancer research, and have raised £100,000 to date. This was something they could control, unlike the cancer, and her family and close friends could be united in this positive way. It never ceases to amaze Christy how her local community always rallies together to support fundraising events.

Christy has recently joined the National Cancer Research Institute's Renal Clinical Studies Group to help give a patient's perspective on renal cancer clinical trials. She has also volunteered to take part in a buddy scheme so that she can help recently diagnosed renal cancer patients with their journey.

Christy hates cancer, especially renal cancer, but it has brought a lot of positivity and perspective into her life. She has met some amazing people on her journey and it has made her a stronger person today.



**James Whale Fund for Kidney Cancer**  
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James Whale Fund for Kidney Cancer was established in 2006. It seeks to reduce the harm caused by kidney cancer by increasing knowledge and awareness, providing patient information and by supporting research into the causes, prevention and treatment of the disease we also aim to reduce the prevalence and impact for future generations. To achieve this, we work closely with patients, nurses and doctors to identify patients' needs and help ensure they are being met by delivering various professional and educational programmes. We provide support in a variety of ways including our website, telephone line for patients and carers, forum, literature, patient support grant and our UK patient awareness days. We have recently launched a new buddy scheme.

We also represent patients in the political arena and regularly lobby government on their behalf at Westminster, the Welsh Assembly and the Scottish Parliament.



**Clive Stone MBE lives near Oxford in the UK. He is 67 years old and was previously an international bank auditor with a large global bank. Clive was diagnosed with clear cell renal carcinoma in 2007, and joined the Kidney Cancer Support Network soon after to help UK kidney cancer patients gain access to cancer drugs. Clive's determination to make sure his fellow patients had access to the latest clinically effective drugs has been inspirational, and to this day, despite his own situation, Clive is still advocating on their behalf. This is Clive's story ...**

Clive was diagnosed with renal cell carcinoma in July 2007, at the age of 59, after blood tests and an MRI scan following breast pains, an unusual presentation. He had a right nephrectomy for a stage pT3b, grade 3 renal cell carcinoma. He developed suspected metastatic disease by the time of the follow-up CT scan in September 2007, with lung tumours. He now has metastatic cancer in his lungs, pelvis, spine, liver, and sacrum, with disease progression in his bones.

He's had several surgical operations to remove tumours elsewhere, including being treated with the excellent Gamma Knife® to successfully treat 36 brain tumours, in addition to three he had removed by open brain surgery. That's 39 brain tumours removed to date, due to the care of his doctors and nurses, his positive outlook, and his Christian faith, which helps him get through each day and is a great comfort.

For Clive, the diagnosis was a great shock, as it is for many, as both he and his wife, Jan, were regular walkers who kept themselves fit with visits to the gym, and Clive was a swimmer. He had just taken early retirement from a

stressful role in a bank, and his wife had retired from Cancer Research UK accounts department. He could find no trace of any hereditary renal cancer in his family, although his father died at 37 when Clive was a baby. His Death Certificate is marked 'acute rheumatoid arthritis', although Clive's mother said that as a lorry driver he smoked about 30 cigarettes a day!

Unfortunately, Clive's wife died from rare triple negative breast cancer, without the chance to see their first wonderful granddaughter or be around to help their daughter, which only mothers can do. So in a way, Clive feels guilty and pretty useless in that he wasn't taken first, and he thinks it's Jan who now motivates and inspires him to try and help others with this dreadful disease.

A few years ago, Clive was asked by his oncologist to take on the Chairmanship of the local support group, Friends of Renal Oncology Group (FROG). FROG set up a campaign team as four new drugs for kidney cancer had just been declined by the UK National Institute for Health and Care Excellence (NICE). So 100 patients went to NICE headquarters,

in August 2008. Their main achievement was persuading NICE to eventually make sunitinib available for all, rather than just in selected postcodes. Unfortunately, Clive hasn't been able to attend FROG for a few years now due to his disability.

In 2010, Clive's MP and Prime Minister, David Cameron was moved to introduce the Cancer Drugs Fund (he says inspired by Clive after drawing attention to the plight of cancer patients), and so far over 70,000 patients have been helped by this fund. Previously, Clive had taken groups of patients to see him and explained how they had been left with no effective treatment options for rare types of cancer. Clive was delighted and honoured to later find that Mr Cameron had supported an MBE for his efforts in helping cancer patients.

Clive had to pay £30,000 for two of his Gamma Knife® treatments because he was refused funding. Clive went to see the Prime Minister who agreed this treatment should be free for all from now on. So sometimes Clive has to pinch himself to confirm that he is still here and able to look after himself, having survived so many brain tumours!

There is so much for Clive to live for, and so many reasons to continue fighting. Recently, Clive was honoured to be asked to be one of the Trustees of the Kidney Cancer Support Network, who do a first-class job for patients. He has been writing a regular column in the Oxford Mail for many years in an effort to show that having cancer is not the end of the road, and it's so important to remain positive.





**By kidney cancer patients  
For kidney cancer patients**

[www.kidneycancersupportnetwork.co.uk](http://www.kidneycancersupportnetwork.co.uk)

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The Kidney Cancer Support Network (KCSN) is unique; we are the largest patient-led and patient run charity for kidney cancer patients, carers and families in the UK. We are dedicated to supporting people affected by kidney cancer by providing up to date information and sharing our experiences of kidney cancer. We strive to improve the lives of patients by advocating for the best possible clinical care and treatment and by providing personal and practical support and advice to kidney cancer patients.

The KCSN was founded in 2006 by 2 cancer patients Rose Woodward and Julia Black who recognised that patients themselves were best placed to understand the worries and fears of other patients. The charity provides safe and easily accessible ways for kidney cancer patients to come together and ensures that no-one has to face a diagnosis alone.

The KCSN works to bridge the gap between the hospital team and the day to day reality of coping with kidney cancer and our members tell us being part of the KCSN has been life changing for them. We work collaboratively with Government and regulatory bodies, clinicians and other cancer groups to secure the best possible care and outcomes for kidney cancer patients.



**Bryan Lewis was diagnosed with kidney cancer in the summer of 2007, when he was just 46 years old. At the time he was the new father of one-year old twins, and had recently been promoted at a leading national trade association. He is married to a wonderful and smart woman, and lives in Philadelphia, Pennsylvania, USA. Bryan and his family had just returned from vacationing in the Rocky Mountains in Colorado. Here is his story ...**

In July 2007, Bryan noticed blood in his urine whilst at work, and thought it maybe from one of the juices he had at a meeting. The cranberry colour continued throughout the day. That evening, Bryan attended the local hospital emergency room. After a two-hour wait, the doctor returns and says they believe he has kidney stones. To be safe, the doctor recommends a CT scan. Another 2 hours later, the CT scan shows a tumour, likely to be cancer, and Bryan is asked to return to the urology department the next day.

When trying to recreate the moments and minutes after hearing that statement, Bryan admits that his memory is sometimes crystal clear and then other times it blurs: 'Cancer. I'm sorry did you just say CANCER?' There is no history of cancer on either side of his family.

His grandfather lived to be almost 101. His parents are both active and in their late 80s.

Ground zero; Bryan's journey begins. But in reality the journey involves many others: spouses, children, extended family, friends, neighbours, medical staff, fellow patients etc.

Upon returning to the urology department after a sleepless night, the doctor matter-of-factly informs him that he needs surgery immediately and he is scheduled for a radical nephrectomy a few days later. The surgery was a success and he is released 4 days later.

During his follow-up visits, Bryan is referred to the oncology department. During surgery metastatic disease was found in the surrounding lymph nodes and going up towards the chest and thoracic area. His optimal course of treatment was to consider taking sunitinib to help keep the tumours in check and stop them from growing and spreading. He was informed he could (and should) get a second opinion.

After searching the Internet (which can be frightening for the uneducated oncology patient) he went to see kidney cancer specialists in Philadelphia and New York. Both agreed; sunitinib was his best bet.

The histology of Bryan's tumour was interesting; it appeared to have both clear cell and papillary characteristics. The US National Institutes of Health (NIH) was interested in the histology and agreed to take a look at his cell slides and have Bryan come in for further analysis. Most of the NIH oncologists came down on the side of sunitinib, but one doctor made the case for surgery due to Bryan's age and overall good health. Bryan and his wife decided to try surgery.

After 13 hours on the operating table, a week in the intensive care, and several weeks in recovery, Bryan went for his 3-month scans and got the all clear. Months later, there was no evidence of disease (NED). Now, 8 years later, he has annual scans and is still NED.

Early in his journey, one doctor gave Bryan some poignant advice: '.....remember this; we are in the practice of medicine. We do not know everything.' Bryan's advice is to: 'Take charge of your own situation. Take copious notes of every meeting and appointment. Ask questions. Get answers. Seek out multiple opinions. Find kidney cancer specialists. There are dozens of types of cancers. Changes and breakthroughs are happening daily in oncology. Many doctors, even the best, cannot read up on everything going on in the cancer universe. Urologic oncologists are focused in

this area. Search. Study. Ask. Join a patient group. Join Smart Patients. Talk to your doctors and nurses. Get involved. Get information. Only you can take charge of your situation.'

A couple of years ago, a good friend of Bryan's said: '.....after all you have been through, you need to give back.' That was the spark to support Action to Cure Kidney Cancer and work towards a cure.

Bryan wants to thank God and also share a sincere thank you to all his family and friends who have prayed for him and supported him during this time. He could not have done it without you.



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Action to Cure Kidney Cancer (ACKC) is a U.S. based non-profit organisation established in 2003 with a mission to increase awareness, fund research, and advocate for increased funding for kidney cancer research and for the rights and welfare of kidney cancer patients.

Our vision is to assist and support finding a cure for kidney cancer.





**Kure It Cancer Research**  
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Kure It Cancer Research was founded in 2007 by Barry Hoeven. After years of living with kidney cancer Barry decided to take action against the lack of funding for research into kidney and almost 90% of all cancers. Beginning with direct support of kidney cancer research at City of Hope, the aim of



**Barry Hoeven is 65 and is fortunate to count many blessings in life. He was raised in beautiful southern California and grew up enjoying the outdoors, with horses on his property and lots of time spent at the beach as a child. He attended college in Los Angeles at the University of Southern California, met his wife there and has three grown-up children. He has been a successful businessman for the last four decades in commercial real estate. He has worked hard, kept his head low, and focused on his goals. The rewards have been many, but early on he felt he lacked a global perspective outside of his myopic business world, which all changed 17 years ago.**

Barry was 48 years old when he was diagnosed with papillary kidney cancer. Surgery followed and good news; the doctors said they 'got it all.' And so it was for six years. Then again, Barry's world shifted, as he knew it; the cancer had spread to his lungs.

He has now been living with stage 4 metastatic kidney cancer for the last 11 years. He has tumours in his lungs, in his bones, and in parts of his abdomen and intestines. And that is really scary, but he always tries to move on, to move ahead through the fear and into action. As you may know, one out of every two men and one out of every three women in the US will get cancer before they die; a very alarming statistic.



Kure It Cancer Research quickly expanded to support ALL underfunded cancer research at leading cancer centers. To-date, Kure It has raised nearly \$4,000,000 and granted funds to 24 research projects in areas ranging from pediatric brain cancer to renal cell carcinoma.

Kure It Cancer Research is committed to directly and immediately funding research at leading cancer centers. \$0.89 of every dollar donated to Kure It is granted out to support the brightest minds in translational research for underfunded cancers, making a difference in scientific advancement and medical understanding as we work collaboratively to fund research, find hope and save lives.

When handed a harsh diagnosis, we all think of the negatives first; Barry did. Questions like: 'Will I live?' 'How long?' And all of the rest of the questions. That's just how we think. Barry has learned a thing or two along the road that has really made a difference for him. He wanted to take action, and so started Kure It Cancer Research to help fund critical research projects that will improve patient outcomes and save lives. Through Kure It, cutting edge cancer research grants are funded across the US for kidney cancer and other underfunded cancers. To date, Kure It has granted nearly \$4,000,000 to some of the brightest cancer researchers in the world today.

But what about the positives of getting cancer? For Barry, cancer has given him a different meaning for life and new priorities. Some of these are as follows:

- 1. Every day is a gift, live it to the fullest***
- 2. Focus on the present and the future, not the past***
- 3. Let the little stuff slide***
- 4. Delegate - others can do it***
- 5. Have fun and more fun, seize the day***
- 6. Spend time on the right things, the important things – family and friends***
- 7. Don't complain, nobody really listens anyway***
- 8. Hopefully, you will have no regrets at the end of the day***
- 9. Never, ever give up! And again, never give up – 'FIGHT ON!'***
- 10. Give back to others, it fills your heart.***

Living with any disease will make you reassess and rethink a lot of things. For Barry, cancer was his wakeup call and it has inspired him to give back – to do something more. It's a top priority for him. He wants to make a difference, and give back every day, if he can. He encourages everyone to do the same.

Philanthropy is in all of us; it's in our hearts. Some of us have had to look a little harder for it, like Barry, but it's there. With a philanthropic heart, you will find that the real joy in life comes from giving. The people that have given back to others are inspirational to all of us. They become role models for good in our life's journey.

Government funding is limited for medical charities, but it is important that we continue to advocate for more support. Private donations are invaluable today pertaining to the funding of innovative research for kidney and other cancers. Barry knows this first hand, because he has been involved with funding vital cancer research projects across the US for the past 5 years.

Barry saw a definition of 'grace' in a newsletter that reads like this: 'Grace is embracing the opportunity to receive something first, and then living in a way that will make a difference in the lives of other people, by making the community a better place.'

Barry encourages everyone to be generous and continue to help fund kidney cancer research today.



**Gary and Susan Poteat are both medical physicists who work every day in community hospitals with people with cancer. They live in Ohio in the USA. While working temporarily in Idaho in 2007, Gary developed a painful tooth that demanded attention.**

**He went expecting to need a root canal – instead a biopsy revealed clear cell carcinoma in his jaw. Here is Gary's story ...**

In all, more than 100 metastatic sites were identified in Gary's lung, jaw, and hip; the primary tumour was in his kidney. He began palliative treatment within a few days, but the outlook was grim. Gary knew that if he had seen a patient with scans like these he would have predicted less than one year to live. The doctors they consulted were focused on 'making him comfortable.' They began thinking about hospice and estate lawyers.

Kidney cancer is notoriously resistant to traditional chemotherapy and radiation. Sorafenib had been on the market for a while, but sunitinib was quite new. There were no articles in the literature to say whether a nephrectomy would help.

Having worked for 20 years in community oncology, Gary began there, but quickly realised he needed to consult an expert. Gary saw a urologist at Emory University who said that while there were no data, his own experience had convinced him that it would be helpful to remove the primary tumour. He quickly had a nephrectomy to remove the large primary tumour. Meanwhile, Gary's brother sought out clinical trials that might help.

One month after the surgery Gary began a course of sunitinib and also a vaccine trial. The experience of embarking on clinical trials gave them a new perspective. They found they could email the lead investigator on the trial and actually get a response from these important physicians. They could speak with them on the phone about strategies for Gary's situation. These connections enriched their knowledge and opened new options.

Over the next 8 years, Gary developed ten new metastatic sites. He had 6 different drugs and 5 courses of radiation treatment. The cancer is reasonably under control, but is not 'cured.' It is a matter of learning to live with cancer.

Gary and Susan have learned some important lessons on what it takes to be a long-term survivor:

First, it takes luck/fate/genetics. These are things beyond our control. How will your cancer respond to the treatment? Even the doctors cannot predict that well. They can give you their educated guess, but even if their prediction is poor, you still might be in that lucky 1%. 'If you don't try, don't do the

hard work, you won't be on the tail of that survival curve. You have to do the research and go through the treatments with no certainty they will work; but if you don't go through them, the outcome is certain. You won't get the benefit unless you try and expend the effort up front.'

Second, it takes partnership between the patient and the doctor. The doctor can prescribe, but then the work of the patient begins. 'You have to COMPLY with the treatment – take every dose, don't cut it down because you don't feel well. You have to COMMUNICATE with your doctor – report that you don't feel well, REPORT all your symptoms. I delayed telling my doctor that I was short of breath on the stairs. That was important information that told him there was a cardiac side effect. Patients sometimes feel they should not tell the doctor for fear they will be taken off the study. But delaying reporting symptoms could mean life-threatening damage to your liver or heart. It is important that the doctors hear about your issues, and hear quickly. They can adjust the medications or change the drug, or help with the side-effects.'

Third, reach out and find others on the same journey. Susan and Gary have spent a lot of time on the online forums. Sharing their anxieties, hearing other people's stories, have been extremely helpful. Reading Mike Lawing's story of long-term survivorship encouraged them to continue. 'If I do everything right, it gives me a chance, not a guarantee,' says Gary.

And most important, take care of yourselves – both the patient and the caregiver. 'It is important to keep ourselves mentally and physically strong. Going back to work, setting goals, helps to keep you going. This is not going to go away. Sometimes there are breaks, but there will be setbacks. You have to be tough and remain dedicated.'

It is now 8 years since Gary's diagnosis, and 3 years off all medications. There is a new spot, which, if it turns out to be cancer, will be his 10th recurrence. He is in training for a triathlon, keeping in shape for whatever comes.

Living long-term with cancer is itself a triathlon. Just when you finish the bike ride you have to start swimming. It's one challenge after the next. But you too have a chance to be a long-term survivor.



**Powerful Patient**  
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Powerful Patient Inc. is a patient advocacy consultancy led by patients and caregivers who have themselves grappled with the complexity of cancer and hereditary disease. Established in 2009 and formally incorporated in 2013, Powerful Patient seeks to assist people with complex medical issues in finding the correct diagnosis and managing their health.

We are deeply involved with kidney cancer, sometimes as a component of a rare multi-system disorder (VHL, HLRCC, BHD,

SDHB, TSC, etc.). All kidney cancer can be sneaky – symptoms rarely occur before the tumour is advanced. There can be clues in the family history. Often some other issue arises first. If you are going to have kidney cancer, it is best to find it early and manage it carefully.

We work with patients with any variety of symptoms to broaden their thinking beyond the one most obvious symptom, to seek out the underlying medical cause and learn how to manage it. All our body parts are connected. Learning how they influence one another is the key to managing our health.



**Karen Ramsey is 55 years old and lives with her family in the USA. Karen never saw it coming and had no symptoms. She felt good and was living a great life. Then she went for a routine ultrasound and the technician found a big mass in her left kidney. After additional scans, it was discovered there was another tumour on her right adrenal gland. After more tests and a biopsy, the doctors finally determined she had clear cell renal cell carcinoma AND a rare tumour called a pheochromocytoma. After conducting research on the Internet, she sent her blood off to be genetically tested. Her worst fears were realised: she had von Hippel-Lindau syndrome (VHL). This is her story ...**

That was the beginning of Karen's kidney cancer journey. At 50 years old, she found out she had VHL - a genetic disease that had been lurking in her body her entire life. And, she had no clue what was going on inside her 'healthy' body. She had been a competitive athlete, ate pretty well, exercised regularly and had kept her weight in the normal range. What was going on here?

VHL is rare, really rare. There are about 10,000 people in the USA, and only 200,000 people in the entire world who have this genetic problem that causes the body NOT to suppress the growth of tumours. The difficulty with this illness is it affects several vascular parts of the body, besides just the kidney. It can cause problems with adrenal glands; in addition, it can wreak havoc on the brain, spine, pancreas, ears, eyes, and reproductive organs. It's hard to stay on top of all the testing and scanning that's required to make sure

no new tumours are growing, or if they are growing, what to do about them! As it turned out, after all the initial scans, Karen found out she also had a tumour in the back of her left eye, and a couple more in her pancreas.

Karen had a laparoscopic adrenalectomy late in 2010 and an open-flap partial nephrectomy in early 2011. She jokes that she looked like the assistant to the magician who sawed the woman in half...and actually succeeded! She had a nine-inch incision from front to back. Her mid-section was starting to look like a roadmap.

Three years passed and she was feeling good again. The anxiety had eased and she'd upped her game on healthy eating and exercise. She'd stayed on track with getting regular scans of all the body parts potentially affected by VHL. And then, the unthinkable happened. Karen's doctor called to say she had a tumour in the temporal lobe of her

brain that was more likely a kidney cancer metastasis than a VHL-related tumour. Not only that, a resident noticed some spots in her lungs (not an area usually affected by VHL) when preparing slides of her abdomen to share at a weekly doctors' meeting: it turns out Karen is a bit of a celebrity and her innards are often featured at these get-togethers. After a follow-up CT, she learned there were so many tumours in her lungs they didn't even bother to count all of them.

The cause? Metastatic renal cell carcinoma (mRCC). Terminal. Karen's projected life expectancy was two to three years. That was in April 2014. She is finally able to wrap her head around the fact that she is going to die earlier than 100.

Since last April, Karen has been taking a daily oral chemotherapy drug (which has some lovely side effects). She has had lung biopsies and her brain tumour radiated.





Neither provided any fruitful results. She is having laser ablation brain surgery soon. Hopefully, it won't affect her language centre and that pesky tumour will be gone for good.

The news isn't all bad; not at all. She has enjoyed many benefits from this experience. She knows she is loved and her relationships with family and friends are most important. She appreciates every day. People want to be of service, so asking for help is a good thing. She is her own best advocate when it comes to getting healthcare support. And, it is possible to find balance between planning for the future and living in the present.

So maybe she won't live to 100, but the quality of her life has been exponentially improved because of VHL and her kidney cancer odyssey.



With a vision of a cure, the VHL Alliance (VHLA) is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by von Hippel-Lindau (VHL). We are the preeminent resource and clearinghouse for patients, caregivers, and the medical community. Through an international network, VHLA supports patients throughout the world.

To help empower patients, VHLA's efforts include: a VHL Handbook; annual and regional meetings; individual support;

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**Website: [www.vhl.org](http://www.vhl.org)**

monthly discussion groups; a mentor programme; social networking; newsletters; and wellness e-news.

VHLA has granted over \$1.5 million to support medical research. While these funds have not yet uncovered an effective pharmacological treatment for VHL, the supported research has resulted in approval of multiple cancer drugs for other cancers including kidney cancer. VHLA has also launched a comprehensive patient database ([www.vhl.org/databank](http://www.vhl.org/databank)) to better understand the impact of lifestyle on kidney cancer.



## Instituto Espaço de Vida

Instituto Espaço de Vida (Institute A Place For Life) is a charitable organisation founded by Christine Battistini, a caregiver and patient, to enable cancer patients in Brazil and Latin America to access the same programmes and support services offered by international patient organisations in USA and Europe.

Instituto Espaço de Vida provides continuous and up-to-date information on a variety of topics, for example:

1. Awareness of policies aimed at improving the quality of life of patients with cancer, blood cancer, neuroendocrine disorders, neural disorders, and other diseases
2. Awareness of the technologies used in the treatment of various diseases that improve the quality of life for patients
3. Awareness of diagnostic techniques and treatment options, new drugs, therapies and maintenance support, the latest advances in research, and information on ongoing clinical studies
4. Promotion of legal support initiatives related to patient rights
5. Preparation, editing, publishing and free distribution of information materials on various diseases
6. Organisation of support groups for patients and their families

7. Promotion of lectures, seminars and educational events focused on various diseases to patients, caregivers, family and medical community
8. Provision of intermediary services to support non-profit organisations and public sector agencies that work in related areas and pharmaceutical companies
9. Maintain 24-hour information for patients, caregivers, family and medical community via video interviews, free publications, articles, and updated news.

### Instituto Espaço de Vida

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## Association pour la Recherche sur les Tumeurs du Rein (ARTuR)

ARTuR (Association pour la Recherche sur les Tumeurs du Rein) is a French charitable organisation founded in 2005 by medical oncologist, Bernard Escudier, and urologist, Arnaud Méjean.

The objective of ARTuR is to support and develop research in kidney cancer, and the clinical management of patients, to improve information for patients and their families, and to help them live with kidney cancer.

In 2010, patients and families joined the charity. These volunteers manage the website and the annual meeting to inform patients and facilitate meetings between patients.

### Association ARTuR

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## Juliet Ibrahim Foundation

Juliet Ibrahim Foundation is a non-profit, non-partisan organisation focused on creating awareness of kidney cancer, malaria, HIV AIDS, Ebola, and other diseases, and providing necessary interventions to ensure a society free of such issues in Ghana and Africa at large.

We understand that cancer, HIV AIDS, malaria and the like, especially kidney cancer, are preventable, and we aim to help those in need of treatment in Africa. Our modus operandi is to offer awareness/education, treatment, and other support that would help individuals dealing with these diseases.

With representation in Ghana, and the United States, it is our goal to build a network of resources that would help the people in Africa suffering from these sicknesses and other related diseases.

### Juliet Ibrahim Foundation

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## ALE Association

ALE Association was founded in October 2004 by the Alverde Castro and Castro Careaga families in Los Mochis, Sinaloa, Mexico, after the death of Ale - son of Luis Eduardo Alverde and Adriana Castro - and the family's extraordinary and painful experience of the reality of organ donation in Mexico.

The aim of ALE Association is to promote the culture of organ donation, and ensure the equipment and human resources to carry out transplants in places that do not have the means to carry out organ transplants.

ALE Association's mission is; to support socially vulnerable people to help them regain their quality of life; being agents of change in public policy advocacy; obtaining the best equipment and human infrastructure for effective organ and tissue donation in Mexico.

ALE Association's view is a modern legal framework for transplant medicine in Mexico that generates an effective and efficient organisation to facilitate organ procurement.

ALE Association's objectives are to be agents of change, providing commitment and capacity for organisation and resourcing, and high professional standards, to integrate the families of donors and recipients with an efficient and effective network of medical institutions; a community of links with the same goal of high level of human and technical service.

ALE Association supports socially and economically vulnerable people of any age and sex, any disease or condition requiring an organ or tissue transplant to keep them alive and give them a good quality of life, and the relatives of these people struggling to make a decent living.

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Website: [www.asociacionale.org](http://www.asociacionale.org)

# Group Locator





diator

Bladder or Kidney Cancer

haus

oundation

CANSA

V Care Foundation

Kidney Health Australia

Please check our website  
for the latest list of organisations  
who have joined IKCC.

Affiliate Organisations can be  
identified by this logo displayed on  
their website and materials.



# Kidney Cancer Basics – A Global Disease

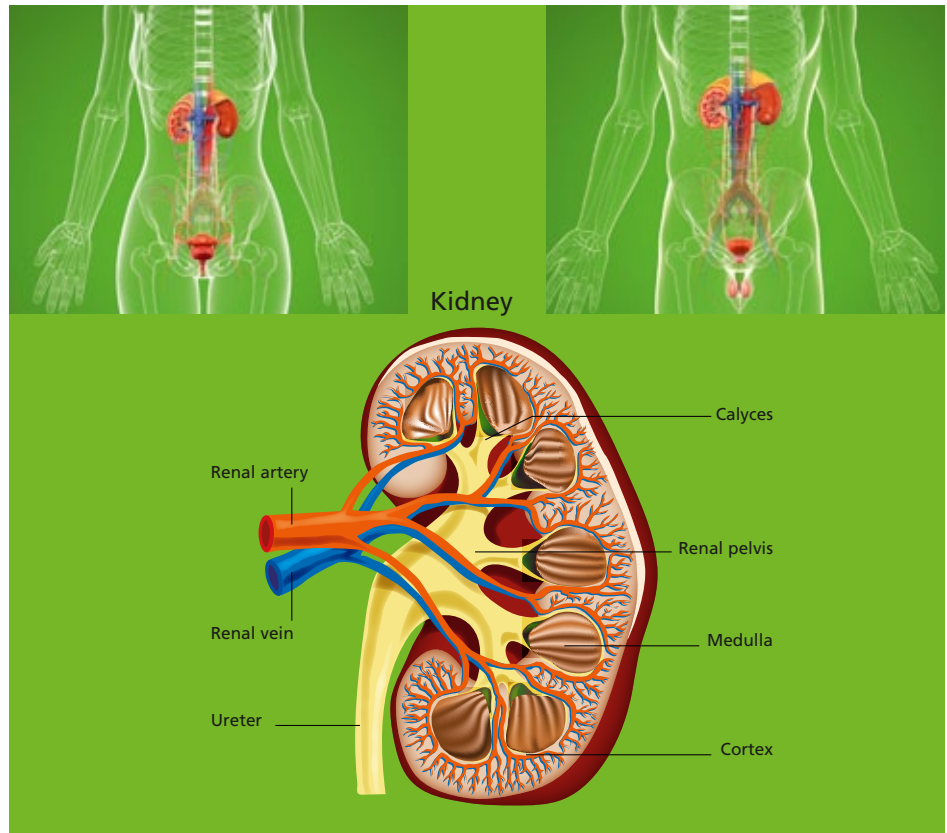
Kidney cancer is considered a rare cancer; worldwide there are about 337,860 new cases of kidney cancer each year, accounting for around 2% of all cancers and making it the 13th most common cancer. Globally, the incidence of kidney cancer has been increasing; in part due to better scanning facilities, although the increase in the prevalence of certain risk factors, such as smoking and obesity, might also contribute.

Cancers of the kidney result from malignant transformation of the urothelium (lining of the collecting system) or renal parenchyma. Cancer of the urothelium is called transitional cell carcinoma (TCC), which is treated in a similar manner as bladder cancer. This article focuses on renal cell carcinoma (RCC) – cancer of the renal parenchyma.

## Types of kidney cancer

There are several different types of kidney cancer. The most common is RCC, which accounts for more than 80% of all kidney cancers. There are eight sub-types of RCC, which are classified according to the appearance of the cancer cells under the microscope:

- Clear cell is the most common sub-type (75-80% of cases)
- Papillary (or chromophilic, 10-15%)
- Chromophobe (5%)
- Collecting duct
- Renal medullary carcinoma
- Mucinous tubular and spindle-cell carcinoma
- Renal translocation carcinoma



© Pictures and Illustrations courtesy of "Das Lebenshaus e.V."

- Unclassified RCC (the latter five are very rare and make up the remaining 5-10% of RCC tumours)

Nephroblastoma (or Wilms' tumour) is a kidney cancer found in children, usually between the ages of 2 and 5.

## Causes

Tumours within the kidney have been found in any age group but are most common in people over 55, and they are more common in men than in women with a ratio of 16:10.

The major risk factors for kidney cancer are obesity (70% increased risk) and cigarette smoking (50% increased risk).

Certain medical conditions and treatments, such as cystic kidney disease, dialysis, renal stones, hypertension, and previous abdominal radiotherapy, can increase the likelihood of developing kidney cancer.

There are also some inherited conditions that can give a higher risk of developing kidney cancer. These include von Hippel-Lindau (VHL) syndrome, Birt-Hogg-Dubé syndrome, and hereditary papillary RCC (HPRCC).

## Worldwide Incidence

The highest rates of kidney cancer are in some parts of Europe (16.67 per 100,000 in the Czech Republic, 13.21 per 100,000 in Lithuania, 12.54 in Slovakia and 11.67 in Estonia), and the USA (11.97 per 100,000 people). The lowest rates are in Asia and Africa (ranging from 0.62 per 100,000 people in Central Africa to 4.21 per 100,000 in Eastern Asia).

The incidence of kidney cancer does not vary significantly in the developed countries, with Canada and Australia reporting incidence rates slightly less than the USA and slightly more than Europe (11.97 per 100,000 in USA, 9.29 per 100,000 in Canada, 9.48 per 100,000 in Australia, 8.77 per 100,000 in Europe).

Worldwide, kidney cancer is the 16th most common cause of death from cancer; in 2012, there were more than 143,000 deaths from kidney cancer (2% of the total). Mortality rates are highest in Central and Eastern Europe, and lowest in Micronesia and Polynesia.

## Symptoms

The classic symptoms of kidney cancer are haematuria (blood in the urine), loin pain and abdominal mass, but only 10% of people present with all three of these symptoms together.

Back pain, night sweats, polycythaemia, and a left-sided varicocele (in men) can also lead to a diagnosis of kidney cancer.

More than 50% of renal tumours are now detected when using ultrasound for non-specific symptoms, such as general abdominal pain, hypertension, malaise, weight loss, anorexia, anaemia, elevated C-reactive protein, or abnormal liver function tests.

Unfortunately, 25-30% of people with kidney cancer present with symptoms of metastatic disease, such as; a persistent cough, frequent headaches, bone pain, or abnormal liver function tests.



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## Methods of Diagnosis

Currently, there are no screening programmes for kidney cancer. The advantage of early detection is successful removal of the affected kidney to prevent the spread of the disease. As the tumour grows and the lymph nodes become involved, the 5-year survival rate decreases from 90% for stage 1 disease to 40-70% for stage 3, and 10-40% for stage 4.

Those who present with haematuria (blood in urine) usually have a urine test to rule out infection. If there is no evidence of infection, or the haematuria continues, the person is usually referred to hospital, and may have a renal ultrasound scan, cystoscopy and/or CT to differentiate between TCC and RCC.

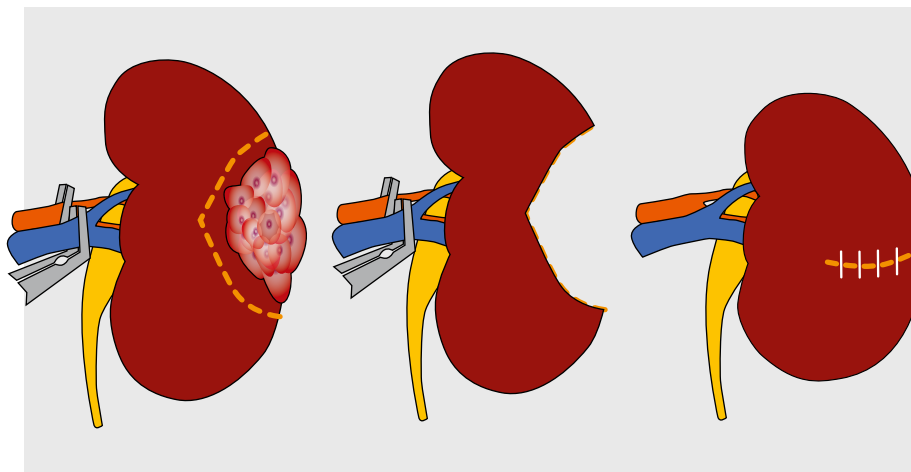
Other tests, such as magnetic resonance imaging (MRI), positron emission tomography (PET), or a bone scan might be undertaken to assess the spread of the disease.

## Staging and Grading

Kidney cancer is graded according to the Fuhrman nuclear grading system as low grade (grade 1; slow growing, less aggressive) through high grade (grade 4; fast growing, extremely aggressive, likely to spread).



# Kidney Cancer Basics – A Global Disease



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Staging using the TNM system is used to describe how big a cancer is and how far it has already spread. T (tumour) indicates the size of the primary tumour (less than or greater than 7 cm) and how far it has grown locally, N (nodes) indicates spread to nearby lymph nodes (1 for a single lymph node, 2 for more than one), and M (metastases) refers to whether the cancer has spread (0 refers to no spread, 1 refers to distant metastases).

Sometimes the cancer is classified as stage 1, 2, 3 or 4 reflecting how large the primary tumour has become, and whether the cancer has spread to lymph nodes or other areas of the body. A stage 4 tumour is often referred to as 'advanced' cancer.

## Surgery

Nephrectomy is usually the first thing doctors consider, and it can cure early stage cancer. The tumour can be removed using partial nephrectomy (or nephron-sparing surgery), to remove only the portion of the kidney containing the tumour, or radical nephrectomy, when the whole kidney is removed. Partial nephrectomies are usually only performed for early stage (stage 1) tumours less than 7 cm in size.

Nephrectomies may be carried out using open surgery or laparoscopic (keyhole) surgery, sometimes using a robot to assist the surgeon (robot assisted surgery).

Ablative techniques, such as cryotherapy (freezing), radiofrequency ablation (heating) and high intensity ultrasound can be used to

treat small kidney tumours. These techniques are less invasive than surgery, and have shorter recovery times; however, they are not widely used and their success is yet to be proven.

## Biological and Targeted Therapies

A number of biological and targeted therapies are used for the treatment of advanced kidney cancer, including immunotherapies, targeted therapies and monoclonal antibodies.

Immunotherapies, such as interferon and interleukin 2 (cytokines), stimulate the immune system to attack the cancer cells. Cytokines were the first systemic treatments for advanced kidney cancer in the early 1990s; however, in recent years they have been superseded by targeted therapies.

A small minority of patients (about 5%) have a long-term durable response to high doses of interleukin 2. This proportion is increased to around a quarter in carefully selected patients. Interleukin 2 therefore still has a place in the treatment of a small percentage of patients where it offers the hope of durable remission.

New immunotherapies, such as PD-1 and PD-L1 inhibitors, and vaccines are now undergoing clinical trials for kidney cancer, having been proven effective for melanoma and non-small cell lung cancer.

The development of targeted therapies has been one of the most promising advances in the treatment of advanced kidney cancer, and is now standard treatment. These drugs block the pathways involved in new blood vessel growth (angiogenesis) essential for cancer cells to proliferate. They also block signals within the cancer cells that trigger cell growth and division.

Targeted therapies include vascular endothelial growth factor receptor (VEGFR) inhibitors (tyrosine kinase inhibitors), mTOR inhibitors, and monoclonal antibodies.

## Radiotherapy

While kidney cancer is widely regarded to be less sensitive to radiation than other types of cancer, recent advances in this field are revisiting the value of radiotherapy in RCC; for example, radiotherapy can be very successful at controlling symptoms and slowing down the growth of metastases in the brain, liver, lung and pancreas. Stereotactic radiotherapy (also called stereotactic radiosurgery or SRS, Gamma Knife®, CyberKnife®, or Stereotactic Body Radiotherapy or SBRT) uses high doses of radiation directed at the cancer using a frame to increase precision and reduce damage to surrounding tissue.

## Access to treatment

Although these treatments are licensed in many countries around the world, access remains a problem. Due to the high cost of medicines approved for kidney cancer, some government reimbursement schemes will

only fund first and possibly second-line treatment. After this, the patient must pay for treatment privately or through insurance, enrol on a clinical trial, or obtain treatment through compassionate use programmes. Some countries have introduced systems to alleviate this problem, such as patient access schemes; however, as development costs soar and kidney cancer becomes a chronic condition, the issue of drug access will be a continuing problem for many patients.

## Research

Research into new treatments for kidney cancer is currently very exciting, especially with the resurgence of immunotherapy in recent years. Checkpoint inhibitors bring renewed hope for the treatment of advanced RCC, and clinical trials with cancer vaccines and more potent targeted therapies show promise. Clinical trials are ongoing in a number of countries with these products.

Some of these drugs are being used in combination with other immunotherapies or targeted therapies to boost their effectiveness.

## National Guidelines for Treatment of Kidney Cancer

A number of countries have developed guidelines for the treatment of kidney cancer, which help to provide a more consistent approach to treating this disease. These guidelines are reviewed at least annually in most countries.



When a country doesn't have guidelines, they might choose to adopt those of another country where the guidelines are established. Guidelines for the treatment of kidney cancer can be found for Canada, the European Union, Mexico, Ukraine, United Kingdom, and United States.

Global kidney cancer statistics can be found at: Cancer Incidence and Mortality Worldwide: GLOBOCAN 2012, International Agency for Research on Cancer: Available from: [www.globocan.iarc.fr](http://www.globocan.iarc.fr)

Further information about kidney cancer can be found on the IKCC website: [www.ikcc.org/types-of-kidney-cancer/](http://www.ikcc.org/types-of-kidney-cancer/)

Information about the new immunotherapy (immuno-oncology) drugs for kidney cancer can be found on the "Ten for IO" website: [www.10forio.info](http://www.10forio.info).

Information about national kidney cancer guidelines can be found on the IKCC website [www.ikcc.org/kidney-cancer-demographics/national-guidelines-and-standard-of-care/](http://www.ikcc.org/kidney-cancer-demographics/national-guidelines-and-standard-of-care/)

# Amsterdam Patient Charter for Global Kidney Cancer Care

The International Kidney Cancer Patient Charter was created by the International Kidney Cancer Coalition (IKCC.org) to ensure that the more than one million people living with kidney cancer worldwide<sup>1</sup> have access to the best available treatment, care, information and support. It is our aim to assist national kidney cancer patient organisations help patients and their families all over the world, get the necessary information to take an active role in the management of their kidney cancer and to gain a better awareness of what they can expect from their treatment and care.

The Charter is based on a survey extended to 34 patient group leaders with a special interest in kidney cancer, located in 20 countries spread over 6 continents. Based on the 22 responses, this charter represents the global response that all kidney cancer patients should be entitled to, in order of reported importance.

The Charter was developed in Amsterdam in April 2014, when the IKCC convened a meeting of leading kidney cancer experts and advocates from diverse geographic regions.

This group discussed the issues surrounding kidney cancer and outlined the universal standards of care that patients should expect, with the goal of enabling patients to become active, informed and empowered participants at every stage of their treatment. All parties noted that the current situation could be improved if those involved in the care and treatment of patients adopted the principles outlined in the Charter on a global scale.

1.	Timely investigation and accurate diagnosis by medical experts with experience in treating kidney cancer
2.	Patient-oriented information and education concerning all treatments including quality of life, side-effect management, pain control, and palliative care
3.	Access to optimal, current evidence-based treatment as suggested by a multi-disciplinary team of medical professionals possessing specialist knowledge about kidney cancer
4.	Regular follow-up care concordant with national and/or international guidelines including appropriate and culturally sensitive psycho-social support
5.	Access to their medical records, including pathology and imaging reports, if requested
6.	Be informed of all available support systems, including patient support tools and local patient support and advocacy organisations
7.	An active role in the decision-making concerning the management of their kidney cancer, e.g. patients should be offered a choice, whenever possible, in the surgical and medical management of their kidney cancer
8.	Information regarding the availability of clinical trials in their country/region
9.	Recognition that kidney cancer can have long-term effects, including heart disease and kidney function insufficiency. Patients should be provided survivorship information, including medical and lifestyle recommendations
10.	Recognition that up to 10% of all kidney cancer tumours are hereditary in nature, as part of familial syndromes, and these patients require specialised and coordinated care over their entire lifetime

<sup>1</sup>338,000 diagnoses in 2012 alone,  
source: [www.wcrf.org/cancer\\_statistics/data\\_specific\\_cancers/kidney\\_cancer\\_statistics.php](http://www.wcrf.org/cancer_statistics/data_specific_cancers/kidney_cancer_statistics.php)

## Signed:

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(Reviewed: Oct 2014)



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

IKCC is governed by a volunteer Board of Directors with members from a minimum of four countries. The Coalition is run according to democratic principles and is not bound by national, political, religious or economic interests. Organisations may apply to become Affiliate Organisations.

## Together we are Stronger

Kidney cancer knows no country boundaries. We all live in a globalised world. Research and clinical trials in kidney cancer are spread across continents and many kidney cancer experts are working on international panels. By working together as patient organisations, we are able to speak as ONE VOICE to represent the perspectives, insights and experiences of kidney cancer patients from around the world. This is empowering to individual patients and also patient organisations.

We have seen from the experience of other rare cancers, that this type of an international network can be very valuable, supportive and inspiring. A lot of groups and organisations, especially in rare cancers have limited capacity and resources and they embrace the opportunity to be part of a larger stronger network which allows them to share best practice, information, and to cooperate and work on similar projects.

## The VALUES of IKCC

**Innovative**

**Culturally sensitive  
(respectful)**

**Ethical**

**Pat  
cente  
demo**

**Professional**

**Collaborative  
but independent**

**Transparent**

## Our Mission

IKCC is a global collaboration to raise awareness, promote research and empower organisations to support people affected by kidney cancer.

## Our Vision

- To empower patient organisations to improve the lives of people affected by kidney cancer worldwide.

## Our Values

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

## Our Code of Conduct

- Our coalition welcomes donations, grants and sponsorship to fund specific projects and to enable the IKCC to grow and develop. IKCC has developed a transparent and robust Code of Conduct to guide the relationships between patient organisations, the healthcare industry and the Clinicians and Healthcare Professionals we work with. The IKCC Code of Conduct outlines our policy on commercial funding and grants and provides a set of firm principles that are used to guide all decisions related to funding of specific projects, meetings and activities.

## Our Objectives

- Raising awareness of kidney cancer as a significant and increasing health issue
- Encouraging early detection and access to quality care
- Enhancing the exchange of information and best practices
- Promoting collaboration and patient involvement in clinical research
- Supporting existing patient organisations and encouraging the creation of new groups



## Joining IKCC

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

Affiliates can be organisations that meet the following criteria:

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



Associated individuals may be clinicians or allied health care professionals working in the field of kidney cancer, onco-nephrology or urology.

Associated individuals have voting rights and are invited to meetings of the Council of Affiliates.



# Acknowledgement



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

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

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

**Please see the IKCC website for further information:**

[www.ikcc.org/about-ikcc/join-the-network/](http://www.ikcc.org/about-ikcc/join-the-network/)

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Layout and Graphics: Herbert Thum, [www.viskon.de](http://www.viskon.de)





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International  
Kidney Cancer  
Coalition

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