

# EXPANDING CIRCLES

in Supporting Kidney Cancer



International  
Kidney Cancer  
Coalition

**2<sup>nd</sup> International Conference for  
Organizations Representing Patients  
with Kidney Cancer  
March 11 – 13, 2012 in Rome, Italy**



**Conference Report**

**Feedback by email from Dr. Purvish M. Parikh (India)  
Medical Oncologist & Hematologist**

**Dear IKCC Steering Committee Members,**

*It was such a wonderful opportunity to be part of the 2nd IKCC meeting in Rome. Indeed it was a pleasure to meet such an enthusiastic and committed IKCC bunch! You have made me a friend and fan of IKCC for life. This is possible only thanks to Vandana recommending my name to you. So special thanks to dear Vandana.*

*I wish other patient advocacy and support groups were as full of joy and positive attitude as you guys are. Congratulations on this immense achievement.*

*I hope that my participation and presentation met your expectations. Any feedback (constructive – positive or negative) would be most appreciated.*

*From this meeting and my interactions with most of you, I am taking back a few lessons:*

- 1. Education is crucial – in a manner that is understood and satisfies patients and their families.*
- 2. Patients don't care how much doctors know, unless they appreciate how much the doctor cares for them.*
- 3. By joining hands we all learn to see things from a new perspective – helps us get out of our silos.*

*I was also surprised by the similarity of some of the problems between developed and developing countries. It reassures me that we are doing a reasonable job.*

*I also understand that there is no need to "reinvent the wheel". We can benefit immensely from the work, information, insights and systems that you already have developed. I look forward to making them available to patients in India and Asia.*

*I would appreciate the opportunity to be in touch with you on a regular basis. Please feel free to contact me any time. Also if you plan to be in my neck of the woods any time, please let me know in advance and we can schedule a coffee together.*

*With personal regards  
Purvish*



**Thank you Dr. Parikh – for your valuable contribution to our conference and your positive feedback. We are very grateful for your support and your friendship.**

**With best regards,**

**The IKCC Steering Committee**

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# **“We come to this conference with our heads and our hearts open!”**

Rosalie Canosa, CancerCare (USA)

## **Acknowledgement**

We would like to thank the following funders who supported the 2<sup>nd</sup> IKCC Conference with an unrestricted educational grant: Bayer, GSK, Novartis and Pfizer.

At the request of the Steering Committee, IKCC received grants from four companies. This funding is not related to any objectives of IKCC or any objectives/content of the 2<sup>nd</sup> IKCC Conference in Rome.

The idea, conception, planning, preparation, realisation, management and the summary of the EXPANDING CIRCLES 2012 Conference was the responsibility of the IKCC Steering Committee without any influence from the sponsors/funders.

We are looking forward to continuing these open and transparent partnerships with the healthcare industry towards achieving our goal of collaboration among independent kidney cancer patient organizations on a global level to better improve the lives of kidney cancer patients at each national level.



## About IKCC

IKCC is an independent and democratic network of patient support and advocacy organizations. The IKCC funding policy is based on our “Code of Conduct”. IKCC was established with the mission of improving the quality of life of patients and their families living with kidney cancer. IKCC provides information, support and assistance to national kidney cancer organizations. All such organizations are welcome to participate.

### **Our Mission:**

Global collaboration to empower kidney cancer patient support and advocacy organizations.

### **Our Vision:**

Improving the lives of kidney cancer patients worldwide.

### **Our Objectives:**

- Improving access to quality care
- Enhancing the exchange of information and best practices
- Promoting collaboration and patient involvement in clinical research
- Supporting existing patient organizations
- Encouraging the creation of new patient organizations.

### **Our Core Values:**

Values are an integral part of every culture – they are central to any organization. The core values of IKCC are:

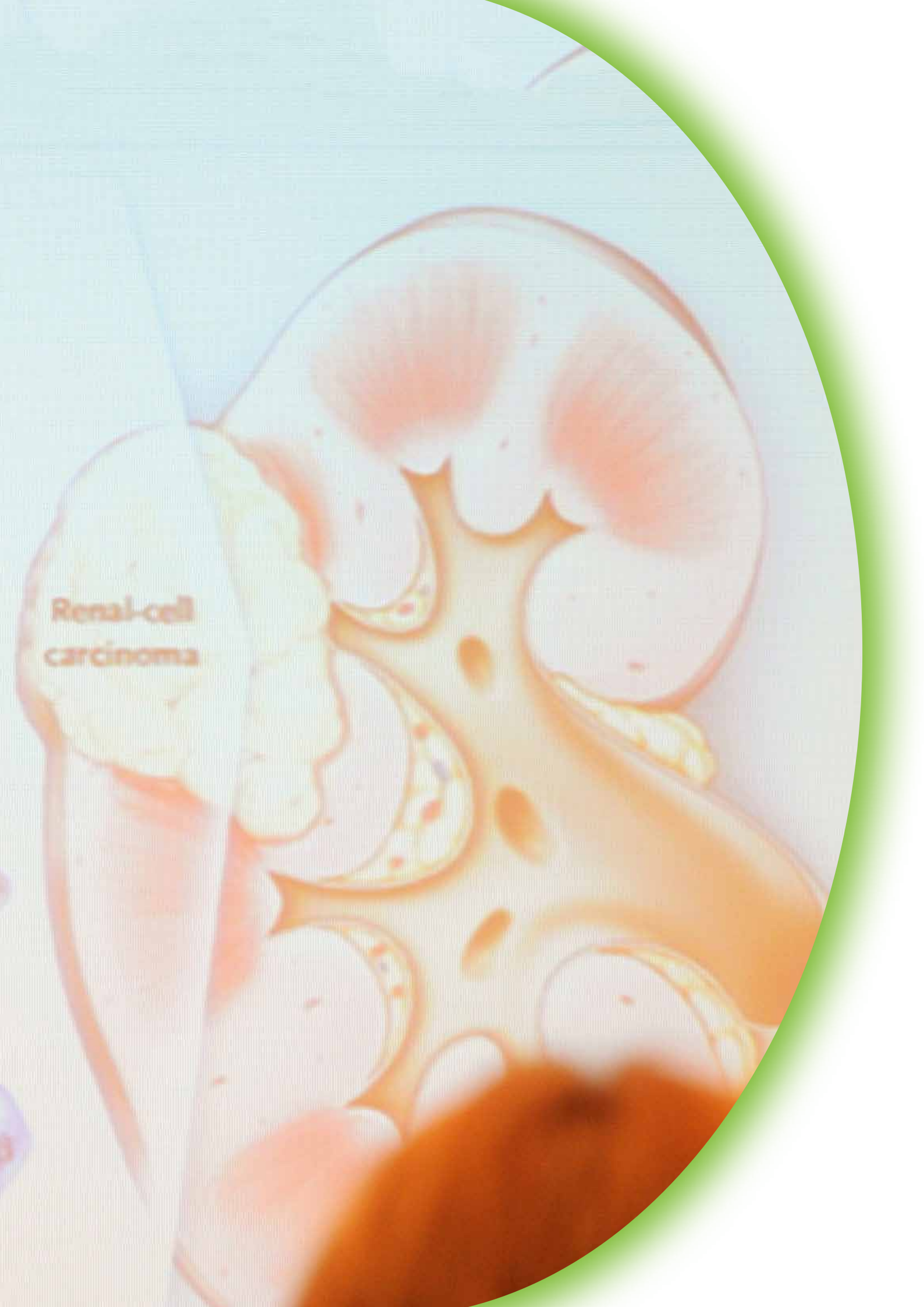
- Patient-centred and democratic
- Collaborative – but independent
- Culturally sensitive (and respectful)
- Ethical and transparent
- Professional
- Innovative.

### **Our Code of Conduct:**

IKCC welcomes donations, grants and sponsorship to fund certain projects and to allow our network to grow and develop. IKCC has developed a transparent and robust Code of Conduct to guide the relations between patient organisations and the industry (including their representatives and consultants). Please see “Code of Conduct” at: [www.ikcc.org](http://www.ikcc.org)



Renal-cell carcinoma



Sunday, 11<sup>th</sup> of March 2012  
 An introduction to Kidney Cancer –  
 especially for newcomers  
 or those needing a refresher

- Prof. Dr. Rachel Giles (NL)
- Robin Martinez (USA)
- Joan Basiuk, RN (CDN)



## Pre-Meeting – Kidney Cancer 101

Cancer is a leading cause of death worldwide. In 2004 there were 7.4 million deaths (around 13% of all deaths) attributed to cancer. The World Health Organization (WHO) has estimated that, based on known risk factors for cancer, more than 30% of cancer deaths can be prevented. Deaths from cancer worldwide are projected to continue to rise, with an estimated 12 million deaths in the year 2030. The latest figures from WHO from 2002 put the new diagnoses of kidney cancer at 208,500 worldwide, accounting for just under 2% of all cancer patients. Knowledge and treatment of kidney cancer varies hugely across the continents. This gap in knowledge is something that the IKCC is trying to address.

The pre-meeting session entitled “Kidney Cancer 101” was specifically designed to share knowledge about the biology of kidney cancer, surgical treatments, and standards of care for metastatic disease. Participants included both experienced patient advocates, as well as newer advocates seeking to learn the core elements of kidney cancer treatment.

Three excellent speakers gave educational talks:

- Dr. Rachel Giles, Professor of Nephrology and Medical Oncology at the University Medical Center, Utrecht, the Netherlands started the session with an overview of kidney cancer.
- Joan Basiuk, R.N, retired Clinical Trials Coordinator Uro-oncology at the Princess Margaret Hospital Cancer Centre in Toronto Canada gave an overview of the surgical treatments for kidney cancer.
- Robin Martinez is a list owner for the global Kidney-ONC mailing list (one of ACOR’s many listservs). Robin has provided support to thousands of kidney cancer patients from Pakistan to Greece, from the U.K. to the U.S.

Highlights from these excellent sessions are included on our website [www.ikcc.org](http://www.ikcc.org). We encourage patient organizations to use/translate/adapt any of the content from the summaries in whichever way supports your community of patients.

# EXPANDING CIRCLES In Supporting Kidney Cancer

From July 11 - 13 March 2012



Dr. [Name]  
[Title]



Dr. [Name]  
[Title]



Dr. [Name]  
[Title]



IKCC

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Sunday, 11<sup>th</sup> of March 2012

- Welcome and Opening Remarks
- Sharing Best Practice Sessions  
(seven presentations from patient organizations around the globe)
- Interactive Session (Roundtables):  
Clinical Trials. An important cornerstone in best kidney cancer care



## 1<sup>st</sup> day: Welcome – Sharing Best Practices – Clinical Trials

Welcome to the 2<sup>nd</sup> Expanding Circles in Supporting Kidney Cancer Conference!

Deb Maskens, co-founder of Kidney Cancer Canada, and Markus Wartenberg, co-founder and Executive Director of the patient advocacy organization Das Lebenshaus in Germany, officially opened the conference and welcomed everyone to Rome.

The IKCC Expanding Circles in Kidney Cancer conference has come a long way since the inaugural meeting in Frankfurt, 2010. Fifty participants from 15 countries (Australia, Canada, Finland, Germany, Ghana, Hungary, India, Italy, Lithuania, Netherlands, Nigeria, South Africa, Ukraine, United Kingdom, and USA) came to the 2012 Rome meeting. The IKCC continues to grow and participants are expanding their own personal circles, those of their organisations and the IKCC into the future.

During the introduction, Jay Bitkower from the U.S. gave a moving tribute to Dr. Ken Youner who had been an IKCC Steering Committee member and kidney cancer patient until his passing earlier this year. “Dr. Ken” was remembered with words and photographs that highlighted his commitment to kidney cancer patients and his joy of life. We will not forget Ken – and we will continue the work he helped start through the IKCC.

The main aims of being together in Rome were to make contact with as many people as possible, to share experiences, ideas and challenges, to learn from each other and to establish an ongoing network of communication that will extend beyond the conference. With these goals in mind, the first session was introduced.

### Sharing Best Practice Sessions

This session was chaired by Jay Bitkower, founder of Action to Cure Kidney Cancer, USA and Vandana Gupta, founder of the V Care Foundation, India. This session enabled seven cancer patient organisations to showcase their work supporting kidney cancer or cancer patients and thereby to share best practices and learn from one another. The session generated some lively discussions and brought to the table some very good ideas for building awareness of kidney cancer and supporting kidney cancer patients.

These organisations made presentations:

- Juliet Ibrahim Foundation (JIF), Ghana (Juliet Ibrahim)
- Suomen Syöpäpotilaat (Kidney and Bladder Cancer section of the Association for Finnish Cancer Patients), Finland (Timo Koponen)
- Kure It Cancer Research, U.S. (Karen Jones)
- Cancer Association of South Africa (CANSA) (Prof. Michael C. Herbst)
- Hungarian League Against Cancer (Dr. Jolan Demeter)
- CancerCare USA (Rosalie Canosa)
- Lithuanian Rare Cancer Patients Advocacy Group (ROLLD) (Dovile Janulynaite)

Details of each presentation are included in Appendix A.



After seven "Best Practice Presentations": Questions from the audience



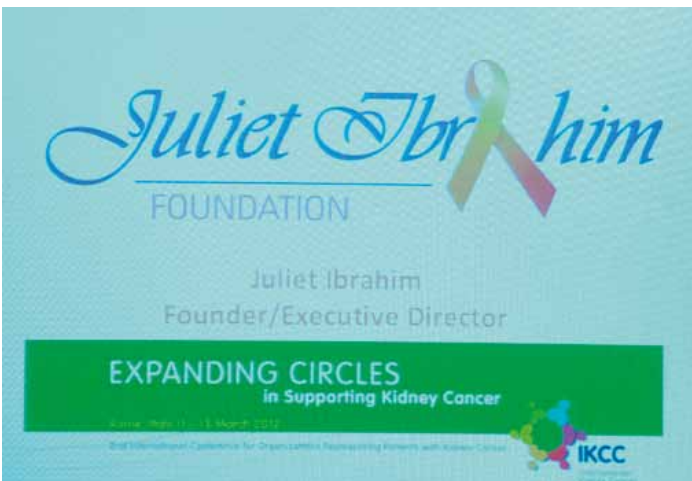
Jay Bitkower,  
Action to Cure Kidney Cancer (USA)  
- moderator of presentations on  
different organizations



Jolan Demeter, MD,  
Hungarian League Against Cancer



Prof. Michael C. Herbst,  
Cancer Assoc. of South Africa



Juliet Ibrahim from Ghana –  
a successful actress. Juliet has  
developed her own foundation to  
fight kidney cancer and kidney  
disease in Ghana and throughout  
Africa.

## Interactive Discussion: Clinical Trials

The last session of Day 1 was a roundtable discussion chaired by Markus Wartenberg, about the importance of clinical trials for patients and caregivers and the current and future role of patient advocacy groups in clinical research. Participants divided up into small groups to discuss each item and then presented the results of their discussions to the other participants.

The main issues raised during the discussion about the role of patients and caregivers in clinical trials were:

- Lack of understanding of the clinical trial process
- Lack of knowledge about the drugs under investigation
- Difficulty accessing information about the trials themselves

Other issues raised were the facts that patients use trials as a means to gain access to a given drug, and that fear and concern about taking part in clinical trials is a hurdle to participation.

The second round table discussed the role of patient advocacy groups in clinical trials. In particular, access to information about clinical trials and the role of patient support groups in the education of patients about the clinical trial process was debated. There was also some discussion about the sharing of clinical trial information among patient support groups.

### Highlights of the discussion included:

Especially in Europe, cancer advocacy groups are becoming more involved in clinical research as early as possible. Patient groups, experts, and pharmaceutical companies are realizing the benefits.

- Patients and patient groups have much to contribute to scientific research. Patients can provide a unique perspective based on their experiential knowledge (i.e. knowledge acquired through dealing with the effects of their condition on a daily basis).
- In the pre-approval and design stages of research, the input of patients enables the development of more efficient trials that address issues expressed by those living with the condition.
- Active involvement in clinical trials can also mean that patients acquire more information on the latest treatments and technologies and may be able to access new drugs and treatments before these become available to others.
- By helping with recruitment and with dissemination of trial results, patient groups are not only supporting research but ensuring that information is presented in a patient-friendly way.
- There are different levels in which patient groups and patient representatives can get involved in the clinical trial process: As a driving force, a co-researcher, a reviewer, an advisor or as an information provider.

For the future, the involvement of kidney cancer patient groups and networks or umbrella organizations like IKCC within the research process will be vital.

A summary of collected results and statements on this topic is included as Appendix B.



*Interactive discussions on clinical trials. Each of four break-out groups was very engaged.*



*Reporters from the tables presented the findings of each group: Andy Thomas from Kidney Cancer Resource (UK)*



Monday, 12<sup>th</sup> of March 2012

- Systemic treatment in Kidney Cancer at a glance:
- Interactive Session (Roundtables):  
The era of oral targeted therapies -  
Therapy and side effect management
- The interdisciplinary/multimodal approach to treat Kidney Cancer
- Kidney Cancer Survivorship Issues



## 2<sup>nd</sup> day: Treatment – Research – Survivorship Issues

### Systemic treatment in Kidney Cancer at a glance

Deb Maskens (Kidney Cancer Canada) opened the second day of the conference and introduced the speakers for the first session:

- Dr. Sergio Bracarda, Senior Oncologist from Ospedale San Donato, Arezzo/Italy
- Dr. Cora Sternberg, Chair of the San Camillo and Forlanini Hospitals in Rome/Italy.

### Dr. Sergio Bracarda

Dr. Bracarda opened the first session with a presentation on the current systemic treatment options for kidney cancer. Dr. Bracarda's presentation focused on how to optimise the use of the currently available systemic treatments for kidney cancer. He talked about the three main classes of treatments in kidney cancer; mTOR inhibitors (everolimus, temsirolimus), VEGF inhibitors (bevacizumab) and VEGF-R tyrosine kinase inhibitors (TKIs, axitinib, pazopanib, sorafenib, sunitinib, tivozanib).

Dr. Bracarda described the use of these drugs based upon prognostic factors (poor, intermediate and high risk), cancer type (clear cell RCC and non-clear cell RCC) and evidence supporting the sequence of treatment (first, second, third, fourth, and fifth line). However, in practice he noted there is a lot of overlap in the use of these agents. The right drug has to be prescribed for the right patient based upon the patient's individual disease, the drug's efficacy and safety profiles, the patient's prognostic risk, and the patient's co-morbidities. The presentation concluded with anticipation of the expected clinical trial results for the TIVO-1 trial with tivozanib, the COMPARZ trial comparing pazopanib and sunitinib, and the RECORD-3 trial to identify the most effective sequence of sunitinib and everolimus.

### Dr. Cora Sternberg

Dr. Sternberg kindly agreed to present on behalf of Prof. Dr. Michael Atkins from the USA who unfortunately could not be present due to a family emergency. The past 6 years have seen a number of new drugs come onto the market for the treatment of kidney cancer and there are now 8 drugs available in the US, most recently with the FDA approval of axitinib at the beginning of this year and 7 drugs approved by the EMA in the EU. Dr. Sternberg summarised the drugs currently available and described the current opportunities for development of systemic treatments for RCC, such as new VEGF agents, dose intensification, biomarkers, and novel targets and treatments.

She described the various ongoing clinical trials comparing the potency of VEGF-R TKIs, the results of which will be available at the American Society of Clinical Oncology (ASCO) meeting in June 2012. She mentioned that the efficacy of the VEGF-R inhibitors may relate to the levels of the drug in the bloodstream and that the dosing of patients could be improved if based upon target blood levels and not a 'one size fits all' approach as currently used.

Biomarkers could be used to identify patients who would derive most benefit and be at least risk of adverse events from a particular drug, in addition to helping to optimise dose and dosing schedules.

Dr. Sternberg described the various potential biomarkers for RCC and the research that she is involved with to identify a genetic biomarker for RCC treatment with pazopanib.

Dr. Sternberg then presented data from research into the new targets and treatments for RCC, such as FGF-R (dovitinib), HIF2 $\alpha$  (the dominant oncogene in RCC), PI3K/Torc2, C-Met (foretinib) and PD1/PDL1 (programmed death ligand-1 immunotherapy).

Dr. Sternberg concluded her presentation by mentioning that there are opportunities for improving the VEGF pathway inhibition with newer second-generation drugs with better therapeutic indices and dosing to blood level, as opposed to one dose for all patients. There are multiple new targets under investigation for the treatment of RCC and it is hoped that new treatments will enable a more durable tumour response. The discovery of biomarkers for RCC is essential for the development of personalised care for kidney cancer patients.

### Discussion

Following Dr. Sternberg's presentation, a very lively and interesting discussion ensued, during which it was stated that education of patients and clinicians about the drugs and how to manage their side effects is fundamental to the optimal use of targeted therapies. However, it is imperative that treatment regimens are easy to understand and translatable between countries. Patients (and to a certain extent clinicians) need to know which drugs are available to them, how to gain access to these drugs, how to manage therapy and side effects and what to expect when taking the drugs. There is a role for patient advocacy groups to impart this information to patients in a means that is easy to understand. In-depth knowledge and experience with targeted therapies is only available at centres of excellence that take part in clinical trials.

### Summary

In summary, the main take-home messages from these sessions were:

- We have come a long way in the past six years with some patients now on 4th, 5th, and 6th line treatment.
- It is important to have the right drug for the right patient at the right time.
- Not all patients are the same. One size/sequence does not fit all.
- Therapy and side effect management is crucial for appropriate compliance/adherence.
- More patients need to be directed to clinical trials to access new drug treatments.
- It is important for patients to have access to a kidney cancer expert if they are not already being treated by one



*Dr. Sergio Bracarda (Arezzo/Italy) and Dr. Cora Sternberg (Rome/Italy) at the end of their very valuable presentations on treatment advancements.*

### Interactive Discussion: The era of oral targeted therapies

An interactive discussion followed, chaired by Markus Wartenberg, on the era of oral targeted therapies.

New targeted therapies such as bevacizumab, everolimus, pazopanib, sorafenib, sunitinib, and temsirolimus have dramatically improved kidney cancer treatment over the past few years - but have also introduced new challenges. Previously, tumour treatments were offered only at clinics and practices, but orally bioavailable drugs are now generally given to patients in tablets or capsules. As a result, the majority of treatments take place at home and the patient is suddenly expected to share responsibility for their therapy. For a "targeted drug" to be successful, i.e. effective in the long term, the patient is expected to stay faithful to the therapy dose and schedule, e.g. must be "compliant" or "adherent".

However, patient advocacy organisations – including those represented at the IKCC conference – have unfortunately found in their daily work with patients that the patient is often given full responsibility. Doctors providing treatment sometimes fail to communicate clearly with the patient, and medication is simply "prescribed". Consequently, therapy management falls by the wayside or is inadequate. As a result, those affected are left alone with their questions, the treatment and its consequences!

### ISSUE: Side Effect Management

A central element of therapy management is the management of side effects. Even though targeted therapies are generally more easily tolerated than many types of chemotherapy, side effects are expected and often experienced.

In our daily conversations with patients we learn that not all doctors actively ask their patients about side effects and quite a few patients often hesitate to openly discuss these side effects with their doctors. An important factor in the success of therapies adherence depends on the management of the therapy and its side effects and therefore on the quality of doctor-patient communication.

### Solutions Discussed

- The patient needs to be educated as to why it is important to take the drug for the schedule prescribed, and how to manage any side effects.
- Communication with the doctor is paramount for good drug compliance; modern systemic oral treatments will not work in a patient who does not take the medication.
- To ensure a patient will benefit from systemic treatment with the best achievable quality of life, patients need practical support from their clinician or oncology nurse.
- Side effects need to be managed as they happen or even prophylactically.
- The drug schedule needs to be maintained for optimal efficacy and tolerability through dose/schedule adjustments by an experienced doctor.

## ISSUE: Adherence to Therapy

If patients are not given information about how to prevent or reduce specific side effects, the next step is not far off: They will skip doses or stop taking the medication, developing their own therapy schedule or even giving themselves 'drug holidays' to minimise the side effects and maintain their quality of life.

There followed a lively discussion about various experiences with drug compliance, centring on communication issues: patients are often unsure why they are taking the medication, they are sometimes fearful of taking the drugs (they might do more harm than good), and there are both financial and personal (lifestyle) costs for prescribed targeted therapies. These situations can be improved with better communication and education of the patient.

Communication between the cancer specialist and the family doctor was also raised as an issue. Often, patients are asked to go to their family doctor if they have any concerns or if they experience a side effect. Family doctors don't have enough experience in cancer (and in particular, kidney cancer) let alone targeted therapies to manage the patient appropriately and to report any side effects to the specialist.

### Solutions Discussed

- It was suggested that an intermediary or nurse could provide support to cancer patients to improve communication between the patient, family doctor and specialist.
- Patient groups have a role supporting the patient with information and giving them advice on where to go for help and support.
- Patient forums are also very good for disseminating information about management of side effects and dose schedules.
- It was also suggested that too much burden is put upon the patient to manage their drug schedule and that compliance could be improved if a nurse proactively follow the patient to ensure the drug is being tolerated and the drug schedule followed. This approach has been shown to be medically effective in other chronic diseases such as diabetes and hypertension.
- Drug packaging and whether this could improve compliance, following the example set by the packaging of birth control pills.
- More information about drug interactions with foods and complementary medicines could also improve compliance.



**A major topic for patients taking oral targeted therapies: the need for expert therapy and side-effect management.**

## ISSUE: Access to Kidney Cancer Expertise

There was some discussion about the impact of the clinician's experience on their decisions to alter the dose and dosing schedules, and the communication pathways between members of the multidisciplinary team regarding this decision. This centred on the definition of progression of disease, how this impacts treatment decisions and how it seems to vary from country to country. The discussion subject turned to access to specialists, the multidisciplinary approach to treating patients, and the role of patient advocacy groups to influence these issues.

### Solutions Discussed:

- Role of patient organisations in creating a virtual "Centre of Excellence" by providing access to information and pointing patients towards experts, second opinions, and clinical trial centres
- From Germany: database on side effect management and compliance for patients and clinicians (initiative of patient organization)
- From Canada: role of Virtual Nursing Network to improve knowledge of kidney cancer nursing, side effect management (initiative of patient organization)

Finally, the impact of physical activity on side effect management was discussed. There have been studies that show exercise is beneficial for the management of side effects such as depression, fatigue, and high blood pressure, and it would be beneficial to add exercise to the cancer care pathway.

### In Closing

IKCC suggested strongly that, in the sense of "targeted patients", everyone – industry, physicians, nurses, carers, pharmacists, rehabilitation clinics and patient organisations – all need to ensure that the management of target therapies is optimised by improving the way they offer explanations, ongoing communication and support.



**Industry is very motivated to learn more about patients experiences and needs. Top left: Dr. Maria Pia Ruffilli, Global Advocacy Manager Pfizer  
Top right: Berit Eberhardt (Das Lebenshaus, Germany)  
Bottom left: Anne Wilson (Kidney Health Australia)  
Bottom right: Dr. Solvejg Nasert, Global Advocacy Manager Bayer**

## The Interdisciplinary/Multimodal Approach to Treat Kidney Cancer

This session was chaired by Berit Eberhardt from Das Lebenshaus in Germany, who opened with an introduction of the two speakers in this session:

- Dr. Purvish Parikh, Medical Oncologist and Haematologist, Managing Director of AmeriCares, Mumbai/India
- Prof. Michael Staehler, Senior Urologist and Head of the Interdisciplinary Centre for Kidney Tumours, Munich/Germany.

### Dr. Purvish Parikh

Dr. Parikh spoke about the current situation in India in terms of access to kidney cancer treatment there. The developing countries account for more than three quarters of the world's population and more than half of global cancers. However, there are fewer qualified oncologists than in developed countries, and each oncologist sees about 835 new cancer patients per year. This is reflected in cancer outcomes, with about a third of patients cured and a third having a poor outcome compared to 50% being cured in developed countries and just over 25% having a poor outcome.

Dr. Parikh described government initiatives to promote early diagnosis of cancer and cancer control, which he has been involved with. He talked about India's contribution to oncology clinical trials, the hurdles to conducting clinical trials in India and the effect of negative publicity on clinical research resulting in desperate patients seeking unproven treatments. Specific challenges included:

- Each oncologist would see 80-100 patients per day in clinic
- Consent forms need to be translated into 8 or 9 different languages
- Only 5% of eligible patients will consent to a trial once it has been explained
- Consent is often video-recorded
- Patient family members play a key role in decision-making.

### In terms of the overall Indian population, Dr. Parikh noted that:

- 55% of the population is very, very poor with no access to any treatment (prevention is the only strategy)
- 15% of the population is very wealthy (can afford treatment at the best centres in India and/or travel elsewhere)
- 30% of the population represents the middle class. This population represents some 350 million people (roughly equivalent to the population of the USA). This is the emerging middle class that may/may not accept treatment or clinical trials.

Dr. Parikh went on to describe how the introduction of generic medicines has enabled people from poor socio-economic backgrounds to access cancer drugs, and how financial constraints influence prescribing decisions. Also, several of the large pharmaceutical companies have patient assistance programmes that provide free medicines for patients from poor socio-economic backgrounds. The first line of treatment is usually the one that gives the patient the best chance of a cure and treatment is optimised when experienced physicians treat patients.

### Prof. Michael Staehler

Prof. Michael Staehler described the situation in Germany in terms of access to kidney cancer drugs, the quality of kidney cancer treatment and the interdisciplinary approach to treatment. The German government (currently) reimburses all kidney cancer drugs and patients have access to the treatments they need. In addition, if phase II trial data are available, any physician can prescribe a drug without the need for board approval. Reimbursement decisions tend to drive the type of drug used, for example intravenous drugs are reimbursed more readily than oral drugs.

The majority of patients in Germany receive sunitinib as first-line treatment and sorafenib as second-line treatment (sorafenib based on experience vs. data). Sequencing data is currently very weak (there are only 2 randomised prospective clinical trials) and sequencing of drugs is based upon experience resulting in some patients receiving seventh, eighth and even ninth line treatment. Prof. Staehler mentioned that anecdotal survival data is often better than the clinical trial data as a result of the strict recruitment criteria applied to clinical trials. Intermediate or low risk patients do very well on targeted therapy in real life settings. Drug compliance is poor and approximately 80% of patients stop taking the drugs due to intolerable side effects. Physicians are not managing the treatment optimally and too few patients are receiving the required dose to treat their cancer effectively. Professor Staehler mentioned that patients often seek a second opinion and move between physicians. Treatment is often guided by side effects, rather than the efficacy of the drug and physicians often do not understand patient needs and under-report the problems of the patient.

Prof. Staehler concluded by talking about interdisciplinary therapy in Germany; there are only 8 interdisciplinary cancer centres in Germany, 5 of which are currently operational. There is only one interdisciplinary centre for kidney cancer, which is headed up by Prof. Staehler. In the interdisciplinary centres, members of the multidisciplinary team are taught in small groups using CT scans and there is a team approach to treatment.



**Left: Dr. Purvish Parikh from India**  
**Right: Prof. Michael Staehler from Germany**



## Discussion Topics

### HD-IL2

There followed a lively discussion about high-dose interleukin 2 (IL2) treatment, which highlighted the different experiences in Germany, the UK and the US with this very toxic drug when used for the treatment of metastatic RCC. In Germany, experience has shown that high-dose IL2 treatment offers no benefit to RCC patients; however, in the UK the Christie Hospital in Manchester has reported remission in 25% of a preselected group of patients. The US also uses high-dose IL-2, but Germany does not. Professor Staehler mentioned that in his experience, all patients treated with IL2 would eventually relapse.

### Role of Patient Advocacy Groups

The discussion moved on to the role of patient advocacy groups in each country. In Germany, Prof. Staehler saw the role as helping patients access experienced cancer centres to receive good quality treatment and disseminating information in a language that is easily understood by patients. Whereas in India, the role is one of lobbying the authorities and pharmaceutical companies to ensure treatment is available for all patients.

### What is Progression?

Discussion showed that RCC has changed the paradigm in oncology. Now treatment needs to go beyond what was previously thought of as progression. Some would see 20-30% growth from baseline scan as true progression. Doctors need to be aware of dosing schedules so they know when to perform scans and of specific characteristics of RCC (i.e. size of lesions is not enough information). There is a danger in switching treatments too soon and going through 5 or 6 treatments within the span of two years, leaving the patient with no further options.

### What Constitutes a Centre of Excellence in Kidney Cancer?

Suggestion: an oncologist who sees 10 cases of kidney cancer per month would be a good number for determining an expert. Patient advocacy groups in developing countries can provide a virtual Centre of Excellence environment by connecting patients and experts across distances.

### Radiotherapy for Metastatic Kidney Cancer

There was some discussion about the use of radiotherapy for metastatic RCC. RCC is not sensitive to conventional radiotherapy, and only very high dose stereotactic radiotherapy has any effect. Conventional radiotherapy can be used to relieve pain but it only has oncological effect when used in combination with systemic treatment.

### Summary

The "Atlantic Divide" in oncology treatment is closing, but there are still some huge differences in how kidney cancer is treated around the globe.

## Kidney Cancer Survivorship Issues

Rose Woodward from the Kidney Cancer Support Network chaired this session along with Andy Thomas from Kidney Cancer Resource, both based in the UK. Rose introduced the session and welcomed the speakers. The main aims of this session were to discuss the definition of kidney cancer survivors, what does survivorship mean to patients and what can patient advocate groups do to support kidney cancer survivors.

### Steve Hindle, Macmillan Survivorship Programme (UK)

Steve Hindle opened the session with a short presentation about cancer survivorship. He started with an introduction to the patient services provided by Macmillan, the UK's largest cancer support charity. He described the situation in England in terms of the number of cancer survivors, their needs and how the NHS is addressing these needs.

Currently, there are 2 million cancer survivors in England, and this is predicted to rise to 4 million by 2030 as a result of an ageing population and more effective cancer treatments. In the cancer care pathway, survivors are in the group of patients undergoing monitoring beyond 5 years. There are about 8,000 patients diagnosed with kidney cancer each year in England.

Steve went on to describe the results of several patient surveys which concluded that the health and well-being of cancer survivors was similar to that of patients with chronic illness. In addition, almost a third of patients reported an unmet need at the end of treatment, which had not improved 6 months after treatment in 60% of cases. The two main issues faced by cancer survivors are feelings of abandonment at the end of treatment and a health care system unable to meet the needs of patients while simultaneously coping with increasing patient numbers.

The National Cancer Survivorship Initiative (NCSI) is addressing these issues with a number of principles, including: personalised care pathways, self management with support and rapid access to a professional, holistic assessment, and information to meet individual needs, promote confidence and patient choice.



Steve Hindle, Macmillan Survivorship Programme (UK)

### Deb Maskens and Joan Basiuk, Kidney Cancer Canada

Deb Maskens and Joan Basiuk followed with the results of their kidney cancer survivorship survey. This focused on early stage (non-metastatic) patients, since 75% of patients in Canada are diagnosed in stages 1, 2 and 3. In the early stages, kidney cancer is treated by community urologists and not in a cancer centre. The aims of the survey were to shed more light on early stage kidney cancer survivorship and to empower patients and caregivers with information. Other aims were to gain a better understanding of the perception of information exchange from the patient's and the urologist's perspectives.

The sample size was significant at 276 patients, 45 caregivers and 40 urologists from across Canada who completed the online survey. The survey showed a disconnect between the recollection of patients and urologists. Areas of significant disconnect included: provision of information about kidney cancer before and after treatment; provision of information about possible health outcomes following kidney cancer surgery; and the emotional, physical and psychological impact of kidney cancer, which was underestimated by the urologists.

Patients and urologists agree there needs to be more education of both patients and health professionals regarding the importance of a long-term survivorship plan and the needs of kidney cancer survivors, in addition to national guidelines for long term follow-up and care. Most urologists cited lack of resources (time) as a barrier to providing information about survivorship, and both patients and urologists agree that a survivorship website would be useful. Following up on this survey, KCC is conducting a media campaign to raise public awareness of the findings across Canada, reaching out to urologists with the results and developing kidney cancer survivorship care plans in conjunction with the Kidney Cancer Research Network of Canada, which they hope will be adopted on a global basis.



*Joan Basiuk and Deborah Maskens from Kidney Cancer Canada presented results of KCC's kidney cancer survivorship survey*

### Robin Martinez, Kidney-ONC (ACOR, USA)

Robin Martinez followed with an emotive presentation of the responses to a survey of the Kidney-ONC mailing list regarding patient experiences as long-term survivors of kidney cancer. Robin defined a long-term survivor as anyone who has outlived their original prognosis. Long-term survivors are often those who seek out the best treatments, participate in clinical trials and actively pursue their own health. They face many issues, such as lack of clinical trials for rare subtypes, the worry of brain metastases, side effects of treatment, and many psychosocial issues.

Robin posed a number of questions to the Kidney-ONC mailing list and received hundreds of responses. Some patients mentioned that lack of energy and side effects of the drugs limit their lifestyle, others were grateful to be alive and treated every day as a bonus, and some were full of praise for their caregivers and felt they also needed support to cope with the stress of caring for a cancer patient. Some patients were grateful for the support from others in a similar situation, while others felt rewarded by being able to provide that support. Most patients found the uncertainty of living with cancer very hard.



*Supporting kidney cancer patients and their relatives for many years via Kidney-ONC discussion list: Robin Martinez (USA)*

## Discussion – Role of Patient Advocacy Groups in Kidney Cancer Survivorship

During the ensuing discussion, Rose Woodward emphasised the importance of patient advocacy groups in addressing the disparity between what the doctor thinks the patient needs and what the patient wants the health care profession to provide. Patient advocacy groups can fill in some of the gaps by providing emotional support, comfort, friendship and encouragement. Surveys, such as the KCC kidney cancer survivorship survey, need to be conducted across country borders to investigate doctor-patient communication issues. Patient advocacy groups could use this information to train healthcare professionals to better relate to their patients. This could also be accomplished through better representation of patient advocacy groups at international conferences such as ASCO and ESMO.

The discussion concluded with some suggestions for an alternative provider for monitoring of cancer survivors to relieve the burden from the physicians, who are limited by workload and time constraints. However, patients should always expect respect from their physician and should not be afraid to feedback their concerns if they are not satisfied with their treatment. Doctors withhold information for a variety of reasons – including patients' capacity to understand and take in the information in an emotionally charged situation – and people forget what they have been told. An important role of patient advocacy groups is to ensure patients have a written survivorship care plan that is based on international standards and is easy to understand.



**Nicole Giroux:** She is dedicated to inform and support the French-speaking patients and their families throughout Canada. Association canadienne du cancer du rein.



**Dr. Ioannis Bouzaklas** Medical Manager RCC, Region Europe, Novartis

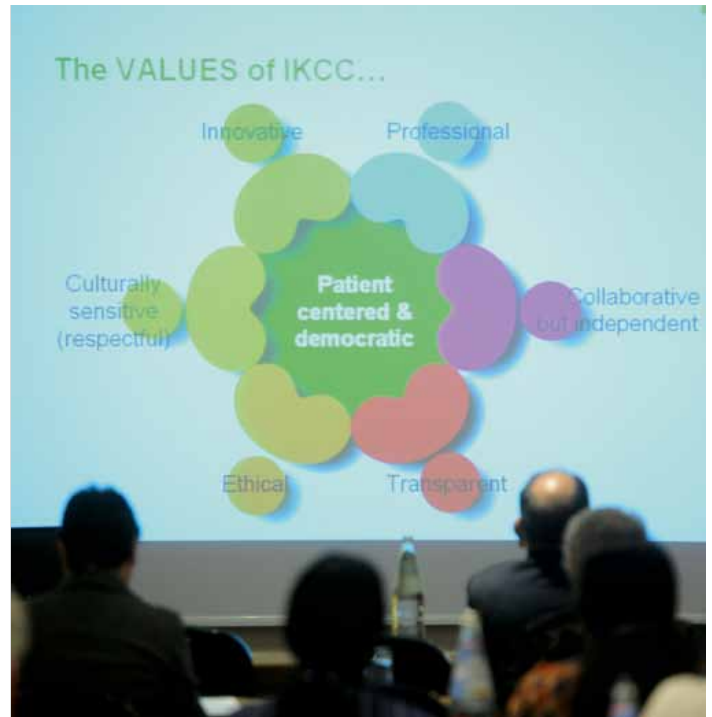


**Geraint Thomas,** Director Patient Relations GSK Europe: Very interested in learning more about adherence issues in kidney cancer



Tuesday, 13<sup>th</sup> of March 2012

- IKCC: History – Present – Future
- Interactive Session (Roundtables):  
Access to clinical excellence
- Patient advocacy: Success factors, challenges and experiences
- Managing upcoming challenges and improving treatment in kidney cancer and in other rare cancers



## 3<sup>rd</sup> day: Discussing Gaps, Needs, Challenges and the Future

### IKCC: History – Present – Future

This short session, chaired by Deb Maskens and Markus Wartenberg, summarised the work of the IKCC to date, talked about the current situation of the IKCC and looked to the future by summarising the goals and objects of the IKCC going forward. Support from the pharmaceutical industry, kidney cancer experts and the IKCC Steering Committee was acknowledged, and the transparency of the IKCC's finances and Code of Conduct for working with industry was highlighted.

The IKCC's main objectives are to improve access to quality care, exchange information and best practices, promote collaboration and patient involvement in clinical research, support existing patient organisations and encourage the creation of new patient advocacy groups. The Steering Committee needs to determine priorities with limited resources over next few months.

The IKCC faces a number of challenges meeting these objectives, including changes in societies and healthcare systems (demographic changes, changing markets, reimbursement schemes, scientific advances, economic challenges etc.), monitoring and building relationships with new patient groups, developing relationships with experts who are not used to working with patient groups, access to human and financial resources for the IKCC, and political challenges from other international patient organisations.

Our immediate goals will be to increase collaboration through our website, stay connected through social media, and initiate global projects as resources allow. IKCC has reached an important milestone in our history where we have outgrown the capacity of our small volunteer base and will be seeking a part-time coordinator to ensure our continued growth.

### Interactive Discussion: Access to Clinical Excellence

Dr. Rachel Giles moderated the last interactive session of the conference on access to clinical excellence. Delegates were split into small groups to discuss and share their experience of access to treatment in their own countries, their goals for the future and how IKCC could support this process.

In The Netherlands, the Dutch Kidney and Bladder Association (Waterloop) has been instrumental in working with physicians, patients, lawyers and government to ensure people have access to quality care resulting in the development of a Quality of Care protocol approved by experts and healthcare professionals and incorporated into Dutch legislation. Waterloop would now like to translate this protocol in English and distribute it for adoption in other countries.

#### Key take-away messages:

- On a national level: patient groups need to work with experts and expert centres to develop strategic partnerships.
- Collecting data and tissue is an important factor for research.
- Legislation and policy change is within the realm of patient organizations.

### Summary of collected results/statements from discussion about IKCC future directions

Further discussions centred on the IKCC's role as a supporter and facilitator of patient advocacy groups. Some of the ideas discussed involved the use of various online tool kits for the education of patient advocacy groups, health professionals and patients, for the exchange of information and sharing ideas and solutions to problems. Ideas:

- International guidelines should be available in local languages.
- IKCC should be part of the international guideline discussions (member organizations should be involved in national guideline discussions).
- Access to treatment: Access to / reimbursement of registered therapies will become an increasing issue in some countries. IKCC can share HTA expertise.
- Conditions within the world are very different: Many countries e.g. Eastern Europe and the third world countries have no access to drugs and treatment
- We need more kidney cancer groups worldwide: IKCC could help to establish them but not own/control them in any way. Promote independence of each national group.
- Use the help of experts to open doors to new groups.
- IKCC could help in training advocates in different countries.
- IKCC could create an online library to share information/material, providing source files that can easily be translated/culturally adapted.

### Patient Advocacy: Success Factors, Challenges and Experiences

#### “Patient organizations need to influence health care policy.” Kidney Health Australia

Gilles Frydman from the Association of Cancer Online Resources (ACOR) in the US chaired this session about the success factors, challenges and experiences of patient advocacy, with a presentation from Prof. Gary Kreps on the work of the Global Advocacy Leadership Academy (GALA).

Professor Kreps spoke about the various complex goals of cancer advocacy groups, which included supporting the information needs of patients, promoting and funding cancer research, educating policy makers, patients and providers, and improving health care policies and practices. Advocates need different skills depending upon their target audience, e.g. research community, healthcare industry, patients, policy makers etc. Other important goals are to support caregivers, family and loved ones, promote cooperation within the medical community, promote prevention and early detection, and disseminate key health information.

Prof. Kreps described the complex and evolutionary nature of cancer information, barriers to dissemination and the need for timely, relevant and accurate cancer information. Advocacy groups have a big role in the dissemination of information that is easy to understand to enable policy makers to make good decisions, influence health behaviours and reduce uncertainty to enhance quality of life for patients, caregivers and providers. To do this effectively, advocacy groups need up-to-date knowledge about the kidney cancer community, care pathways, corporate influence, government and healthcare policies, healthcare systems and other patients groups and charities. Effective health advocacy needs strong leadership and relevant resources.

A training program named GALA is being developed in the USA to supplement leadership experience, support advocacy groups with best practices and political insights, connect leaders to key organisations, promote communication and support collaborative advocacy across disease areas. GALA educates and provides advice for advocates on the intricacies of such things as media, government and corporate relations to organisational administration and fundraising. They are hoping that IKCC will endorse and collaborate on GALA's initiatives, collaborate on the development of training programmes and materials, publicise GALA to advocates and supporters and provide GALA with training on key topics.

### Discussion

During the following discussion, it was apparent that each of the different patient advocacy groups had distinct requirements with respect to support and education. There was some concern that GALA training is America-centric and doesn't take into consideration the cultural differences and unique situations in countries outside America. The GALA programme is a very worthwhile initiative and a nice model that will fit with many patient advocacy groups, but will need to be tailored for each individual country and have a more practical application. The challenges mentioned could also be off-putting for some small patient advocate groups, since they all have a different approach to patient advocacy and very few resources to enable them to address each of these challenges.



*During the interactive discussions: Vandana Gupta from V Care (India)...*



*...and Rosalie Canosa from CancerCare (USA)*

## Managing Upcoming Challenges and Improving Treatment in Kidney Cancer and in Other Rare Cancers

The final session of the conference was chaired by Markus Wartenberg and addressed two very important challenges; HTA = health technology assessment (what does it mean and what are the consequences for cancer patients) and ESMO's action against rare cancers in Europe (a very important European initiative for a better future for patients with rare cancers).

Speakers included:

- Dr. Karen Facey, Health Policy Consultant (UK), Chair Health Technology Assessment International [www.htai.org](http://www.htai.org)
- Robert Schaefer, ESMO Rare Cancers Europe (RCE) [www.rarecancer-seurope.org](http://www.rarecancer-seurope.org)



**Dr. Karen Facey, Health Policy Consultant (UK) discussed how patient advocacy groups can play a role in HTA.**



### Dr. Karen Facey

Dr. Karen Facey opened the session with a presentation on health technology assessment (HTA). Health technology is any intervention to promote health, prevent, diagnose or treat disease or for rehabilitation or long-term care. It includes screening programmes, diagnostics, devices, medicines, surgical procedures and organisation of health care. HTA is the research-based assessment of health technologies in real life situations compared to current best standards of care. Health technology is very country-specific and patient advocate groups need to be aware of the technologies available in their own countries. Various aspects of the technology are assessed, such as cost effectiveness, patient issues and alternatives. The results of HTA are used to inform policy decisions and guide the adoption of new technology by the healthcare agencies.

**“We need to replace ‘patient views’ with ‘evidence on patients’ perspectives’.” (Dr. Facey)**

Dr. Facey went on to describe the importance of patient evidence in HTAs and how patients can become more involved in the HTA process. Health Equality Europe (HEE) produces a guide for patients and their families or caregivers explaining the process and providing advice on how to input. She then described the various methods whereby patient evidence is collected for HTAs and some of the barriers to participation. She emphasised that patient evidence from patient

organisations must be qualitative, robust, well planned, systematic, clearly presented and structured to be accepted by government agencies. Commissioning surveys to social science researchers was suggested.

Dr. Facey concluded by talking about the challenges facing HTA, such as improving the way HTA agencies work with patients, engaging with industry to ensure clinical studies are patient-focused, methods for assessing the value of the technology being assessed, and societal values in HTA. She talked briefly about the work of EUnethHTA and how this will address patient aspects and cross-border health care legislation. She finished by mentioning Health Technology Assessment International, an interest group on patient and citizen involvement in HTA, and how they can support patients in HTAs. HTA is the bridge between scientific evidence and policy-making. Patient input is needed to guide us from where we are to where we want to be.

### Discussion

The following discussion centred around how patients can become involved in HTA, what patient advocacy groups can do to assist patients in this process, and how IKCC can facilitate. HTA is a new burden on patient groups and many do not have the resources to get involved. IKCC could help by sharing information on HTA patient evidence submissions and by connecting patient groups with those who already have experience (e.g., UK, Canada, and Australia).

Online communities are great resources for patient evidence and experience and can be used for HTAs if this is collected in a systematic manner. The value of patient evidence was discussed as being on par with cost evidence and the effectiveness of the technology during HTAs, and patient input is very valuable for approval of drugs on borderline of acceptable reimbursement. The discussion moved on to clinical guidelines as a good way for patient groups to become engaged with the experts in HTA.



**Robert Schaefer (RCE):** *“Rare Cancers Europe (RCE) has been established as a partnership of cooperating organisations that work together.”  
IKCC is a full partner of this active initiative.*

### Robert Schaefer

**“Rare cancers are not so rare – represent 22% of the total cancer prevalence.”**

Robert Schaefer, ESMO Rare Cancers Europe (RCE), gave the final presentation of the conference. Rare cancers are more common than most people think. More than 4 million people in the European Union are affected by rare cancers. Despite the rarity of each of the 186 rare cancers, they represent in total about 22% of all cancer cases, including all cancers in children, diagnosed in the EU27 each year.

Patients with rare cancers are faced with particular challenges, including late or incorrect diagnosis, difficulties finding clinical expertise and accessing appropriate treatments, difficulties carrying out clinical studies due to the small number of patients, possible lack of interest in developing new therapies, high uncertainty in clinical decision-making, and the scarcity of available registries and tissue banks.

Rare Cancers Europe (RCE) has been established as a partnership of cooperating organisations that work together to place the issue of rare cancers firmly on the European policy agenda, to identify and promote appropriate solutions and to exchange best practices. RCE campaigns to implement 39 Political Recommendations on Stakeholder Actions and Public Policies. These recommendations were the outcome of the conference “Rare Tumours in Europe: Challenges and Solutions”. This conference, held in November 2008 in Brussels, was hosted by the European Society for Medical Oncology (ESMO) and organised with other cooperating partners. The conference brought together 150 participants representing a multitude of stakeholders from across Europe. During the workshop sessions, all the conference participants were invited to add their comments to the draft recommendations, which had been prepared in advance by representatives from the cooperating organisations and expert advisers.

Organised by the European Society for Medical Oncology (ESMO) and Rare Cancers Europe, the Rare Cancers Conference held on the 10<sup>th</sup> of February 2012 in Brussels provided a multi-stakeholder platform for rare cancer and rare disease experts from across Europe to exchange views and share insights into what can be done to improve the methodology of clinical research on rare cancers.

In the first period of the initiative ESMO has three main goals;

- to improve methodology of research;
- to improve organisation of health care;
- to improve access of rare cancer patients to new treatments in Europe.

Rare Cancers Europe (RCE) is working with many partners from oncology associations, patient groups and the pharmaceutical industry to address these goals. Robert Schaefer announced during his talk that IKCC was just accepted by the other partners as a full partner of this initiative. IKCC was very excited about this news and honoured and motivated to take part.

### Discussion

During the discussion it was agreed that it is crucial for patient groups to be involved with these activities and to maintain the momentum on the Rare Cancers Europe initiative through collaboration and working together. The difference between North America and Europe with respect to the involvement of patient groups was highlighted and discussed, and it was suggested that ESMO can influence the American Society for Clinical Oncology (ASCO) to include patient advocate tracks in its congresses. The importance of national and international cancer registries was also discussed, especially for rare cancers, and the evolution of the classification of cancer by genotype was touched upon.





*Timo Koponen, The Association for Finnish Cancer Patients*



*Dr. Rachel Giles, Dutch Kidney and Bladder Association (Waterloop) and Dutch von Hippel-Lindau Organisation*



*Top left: Dr. Isabel Duarte, Senior Medical Manager (Pfizer)*

*Bottom left: Christina Claussen, Director Patients Relations (Pfizer)*

*Bottom right: Ashok Sachdev, Kidney Cancer Care Found. (India)*

*Impressions from the interactive discussions and the presentations of the 3<sup>rd</sup> day.*

*From left: Gilles Frydman, ACOR.ORG (USA)*

*Berit Eberhardt, Das Lebenshaus e.V. (Germany)*

*Dr. Gary Krebs, George Mason University, Center for Health & Risk Communication (USA)*





“Kidney Cancer Patients deserve all the help that they can get and I can really applaud the efforts of IKCC towards this goal.”

## Rome 2012: Closing Remarks – Feedback – Impressions

Rose Woodward and Vandana Gupta closed the meeting by thanking everyone for their participation and for making the meeting a great success. Delegates were encouraged to share their stories and best practices on the IKCC website and to contribute to the delegate wish list. The IKCC Steering Committee left the conference with a list of action items and will be looking for volunteers to take the lead on various projects, such as sharing best practices, clinical trials information, and publishing and gathering national kidney cancer guidelines.

### Original citations from participants:

“A wonderful experience! Looking forward to the 3<sup>rd</sup> International conference–IKCC rocks.”

“I thank everybody that I could take part in this conference! I learned a lot from other countries and other people. I hope we will meet again.”

“The future of improving treatment and better tailored research for kidney cancer will depend on a very close cooperation between all stakeholders. This conference shows very clear, that kidney cancer groups are very mo-

tivated to work hand in hand together. But it demonstrates also, that IKCC is becoming a peer to peer partner to the experts and the healthcare industry.”

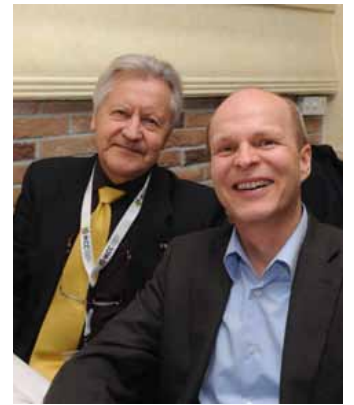
“I am thankful to IKCC for bringing people together from all over the world to learn from each other.”

“Wonderful conference - very inspiring!”

“Very enjoyable and well-organised. Thank you!”

“I want to thank IKCC for the opportunity to attend this meeting and to opening my eyes to the needs of Kidney Cancer Patients. Congratulations on a wonderful conference.”





*Breakfast, coffee break, lunch or Italian dinner:  
Valuable time for networking, making new friends, having fun or learning  
more about the daily life in countries like Ghana or India.*





### Juliet Ibrahim Foundation (JIF), Ghana

Juliet Ibrahim, the founder and executive director of the Juliet Ibrahim Foundation, gave a short presentation on the work of her recently launched, non-profit, non-partisan organisation that has a focus on creating awareness of kidney cancer and providing cost-effective treatment for individuals with kidney-related diseases in Ghana. The organisation was operational in October 2011 and was launched in a star-studded event on 26th December 2011.

Their mission is to create awareness of kidney cancer and provide necessary interventions to ensure a kidney cancer free society. Their goal is to help build continuous awareness and prevention of kidney cancer in the community, and their target population includes individuals suffering from kidney diseases who cannot afford treatment.

Juliet outlined a number of initiatives that her organisation is working on:

**END IT NOW:** a health campaign program that brings together music, movie and TV stars to create awareness in the general public about kidney cancer. This program will utilize the network of influential entertainers as program ambassadors to drive the message about change of lifestyle and alternative behaviours that would decrease the susceptibility to kidney cancer.

**KNOW:** a database of scientific information and publications about kidney cancer that will be made available to medical practitioners and professionals. On the KNOW platform, medical practitioners and professionals will be afforded a forum to discuss the latest interventions and treatment and best practices applicable to the local area of service.

**OCTOBER TO REMEMBER:** JIF was conceived in the month of October so during this month, JIF plan to hold an annual concert aimed at raising funds to support the mission of the organisation and its operations.

JIF uses social media such as Twitter and Facebook to build awareness of the organisation and the work it is doing and for fundraising initiatives. They are also applying for grants and looking for corporate supporters. They plan to raise funds through fundraising events and galas with silent auctions and raffles. They also raise awareness through the use of MyCloud – an SMS based system that solicits subscribers to follow JIF for information about kidney cancer.

As a famous actress, Juliet has used her contacts in the entertainment industry to help create awareness of kidney cancer. She has recently produced an excellent kidney cancer awareness music video with appearances from top musicians and film actors to generate media attention and to deliver a message that will leave a lasting impression. The video is available to download from YouTube.

<http://youtube/bBe5C8jbyEE>  
[www.julietibrahimfoundation.org](http://www.julietibrahimfoundation.org)



### Suomen Syöpäpotilaat (Association for Finnish Cancer Patients), Finland

Timo Koponen introduced the Finnish Cancer Association, Suomen Syöpäpotilaat, which has been supporting cancer patients in Finland both psychologically and socially for more than 40 years. In Finland, there are 12 regional cancer associations that play an important patient support role, both regionally and locally.

Suomen Syöpäpotilaat has taken the initiative to establish 9 patient network groups for different cancer types, each network being led by a patient leader supported by professional staff from the association. Timo leads the kidney and bladder network that was established 4 years ago. The network holds seminars about twice a year – these are one-day events with lectures from medical doctors specialising in oncology, urology, psychiatry etc. The seminars encourage patient discussion and exchange of experiences among patients, an essential part of networking. On average, about 40-50 participants attend the seminars and a professional who is available for individual consultation supports each seminar. The seminars are reported on the association's website in addition to the patient network.

The organisation also produced an information book for kidney cancer patients that is available as hard copy or as a download from their website, in addition to two general cancer magazines that focus on patient stories and professional articles about cancer.

The Finnish government is in the process of putting together a National Cancer Strategy, which establishes a National Cancer Centre where cancer associations will have an important role in structure and function. In the current European and global economic climate, the Finnish government has a difficult task deciding how to allocate public resources and deciding on priorities, such as cancer screening programmes and post-treatment follow-up of cancer patients. With the recent advances in cancer knowledge, treatment options and genetic research, cancer research should have high priority for the government and sufficient resources.

In Finland, the cancer associations have a major responsibility in the rehabilitation of cancer patients, with the government playing a key economic role. Patient associations have an essential role in overall cooperation between the public and private sector, which is becoming more important due to the increasing incidence of kidney cancer in Europe (60,000 patients per year), Nordic countries (2,600 patients) and Finland (800 patients).



### Kure It Cancer Research (Karen Jones, United States)

Karen Jones presented Kure It, a non-profit organisation dedicated to funding research into kidney cancer and other underfunded cancers. Kure It raises money from the private sector and redirects these funds to cancer researchers conducting innovative projects. Funds are raised in a variety of ways including annual fundraising events, local fundraising efforts, community and family foundations and projects with the self-storage industry.

Karen explained Kure It's relationship with the self-storage industry and why this industry was chosen as a fundraising partner. In 2011, Kure It's partnership with the self-storage industry raised over \$200,000. There are 46,500 storage facilities in the US alone, with over \$20 billion in annual revenues in 2010. There are an additional 12,000 facilities worldwide. The industry has a broad geographic and demographic reach – nearly one in ten US households rent a unit at a self-storage facility. Kure It founder, Barry Hoeven, is the President and Owner of US Storage Centers. Barry's personal battle with kidney cancer and his commitment to raise funds through the self-storage industry has been featured in a national trade magazine for the self-storage industry.

Kure It has three main initiatives for raising funds in this partnership;

- 'Store for the Kure' is at the ownership level; self-storage facility owners raise their rents by \$0.50 per unit, per month and the company donates this extra rent money to Kure It.
- 'Round Up for Research' is at the tenant level; tenants are asked to make a recurring monthly contribution or to round up to the next even dollar.
- 'Charity Storage' capitalises on the popularity of hit TV shows such as 'Storage Wars'. Donated items are collected in a charity storage unit and the unit is auctioned off. Proceeds from the sale are given to Kure It and other local charities.

Self-storage associations give Kure It complimentary exhibition space and allot speaking time at trade shows and conferences. In return, Kure It promotes the association's activities and membership benefits. In addition, vendors create unique percent-of-sale and other fundraising activities in support of Kure It. Unique annual fundraisers hosted by Kure It or others in the community account for roughly \$125,000 each year.

In 2011, Kure It financially supported projects at City of Hope's Beckman Research Institute and Cedars-Sinai's Samuel Oschin Cancer Center. Karen's presentation gave all attendees excellent ideas for fundraising that can be culturally specific, innovative, and profitable.



### Cancer Association of South Africa (CANSAs)

Professor Michael C Herbst, Head of Health, introduced the work of the Cancer Association of South Africa (CANSAs). He concentrated his presentation on the CANSAs Dignity Tool®, a web-based instrument with the capability of measuring the aspects or 'constructs' that contribute to the dignity of a person diagnosed with cancer.

The term 'best practice' refers to those practices that have produced outstanding results in a particular situation and which could or may be adapted for use in another situation. The CANSAs Database with Dignity Tool® is an example of best practice introduced by CANSAs.

The database contains data on biographical details, lifestyle (including smoking, alcohol use and sexual orientation (not compulsory)), ICD-10 medical coding reference, patient history, treatment, care and follow-up (from diagnosis onwards), in addition to the Dignity Tool®.

The Dignity Tool® had to be representative of the total South African population (multiracial) - the Rainbow Nation. It had to appeal to all involved in diagnosis, treatment and care of cancer patients;

- Representative focus groups were used to identify constructs.
- Group of experts was used to determine the scoring of constructs.
- Computer software experts created the software .
- Pilot study to determine applicability and trustworthiness.
- Training of users.
- Implementation.

The CANSAs Dignity Tool® comprises a graphic illustration or 'spiogram' of those aspects that affect the dignity of any adult (over the age of 18) diagnosed with cancer (and who is seen as a cancer survivor). A CANSAs Paediatric Coping Tool® is currently being developed for children up to the age of 18, which will measure the ability of the children to cope with their diagnosis, treatment and care.

There are 8 main constructs that have been identified for use in the CANSAs Dignity Tool® that are often shared by survivors:

- Communication and communication problems
- Family harmony
- Fear
- Having to 'let go'
- Unfinished business
- Last wishes
- Basic care
- Nursing care

More than one 'spirogram' of the same individual can be called up from the system and can be superimposed by the software so that a comparison can be made between two or more evaluations of the same patient to detect improvement and/or deterioration on one or more of the constructs.

Uses of the Dignity Tool®:

- Replaces subjective assessment with structured and objective assessment
- Found to be an excellent instrument to manage effective palliative care for seriously ill and dying people by caregivers
- Being a web-based application, it assists in the management of the palliation of cancer patients anywhere
- The uniform language of the instrument helps caregivers to formulate problem statements and helps supervisors to render accurate solutions to patient problems
- Can be used as a framework to better understand the basic needs of seriously ill and dying people

The Dignity Tool® gives a good indication of how cancer survivors react if their dignity was impaired. Caregivers reported that the use of the tool had an invigorating and positive effect on them. There was a suggestion that 'burn-out' due to emotional stress experienced by caregivers might be lessened. The Dignity Tool® could also help supervisors to separate those caregivers who were ready to support client needs from those who would better be left with more menial tasks.

CANSA has the support of the South African Oncology Consortium (SAOC) who has signed a memorandum of understanding (MOU) that they will enter all their patients diagnosed with cancer into the CANSA Database. All oncologists in South Africa belong to SAOC. SAOC will also make use of the CANSA Dignity Tool® in providing treatment and care to their patients.

CANSA is currently getting other partners involved as well, e.g. urologists and other medical specialists and doctors who treat cancer patients.

Michael's stated interest in attending the IKCC Conference was to learn more about the specific needs of kidney cancer patients and to work towards establishing support for kidney cancer patients in South Africa.



### Hungarian League Against Cancer

Jolan Demeter presented the Hungarian League Against Cancer (MRL), which was founded in 1990 as an independent, non-profit non-government organisation (NGO). The president is Prof. Dr. Tamas Simon. It is the biggest anti-cancer organisation in Hungary with 43 local organisations, five supporting services and more than 5,700 members all over the country.

The MRL's mission is to protect health and fight against cancer with every means through raising awareness, improving information, education, trying to strengthen primary and secondary prevention, patient's rights, providing psychological support for cancer patients, supporting cancer research, lobbying in every forum and fundraising for these items.

State subsidy of NGOs is restricted, as are funds from other sources. Until recently, inexpensive National Health Insurance covered the healthcare of the Hungarian people, even the cost of cancer treatment. Since some of these expenses are very high, patients are denied access to certain medicines, such as everolimus or some breakthrough pain killers.

Recently, there has been another big change. The hospitals have been nationalised and it is hoped that this will improve access to medicine. For non-subsidised, unaffordable drugs, patients can apply for funding from the government.

In Hungary there are 2,200 new kidney cancer patients yearly, and two thirds of them are men. For most patients (about 60%) initial treatment is surgery— radical or partial nephrectomy— and no other therapy is necessary. Due to advances in technology in recent years (ultrasound, CT, MRI), kidney cancer can be diagnosed earlier, quite often incidentally when a patient has an examination for pain in their side. The survival rate is about 60% in Hungary.

The main issues facing Hungarian patients with metastatic kidney cancer are access to second-line treatment (such as everolimus) that is not covered by medical insurance and travel costs to one of only 8 centres in Hungary where treatment is available. The Hungarian League Against Cancer is lobbying to solve these problems.

Jolan described two cases, the first being the loss of her brother to kidney cancer. Unfortunately, her brother did not go to doctor in time (his urine was red for months but he thought that this was a side effect of a medicine) and when he eventually saw his doctor he had a large painful tumour in his abdomen and it was too late for any treatment. He died a year later after a lot of suffering. It was 1985 and there were no medicines for metastatic cancers at the time.

However, these days the survival rate is about 60%, but there are still some very sad cases; a dentist whose father had died of infarct at age 45 was concerned that he had inherited the condition from his father. At 46, he too had an infarct and was examined regularly at the clinic. Some years later in the US a 4 cm kidney tumour was found. He had a



nephrectomy and he recovered and was in good health for 8 years. A few months ago he had a CT scan for a large painful tumour in his sternum; a metastasis. Metastases were found in the lung, liver and peritoneum too. It was too late for any treatment and he died within 3 months.

The MRL supports patients and caregivers in a number of ways:

- Information is very important; the MRL organises various meetings and training courses, such as postgraduate courses for GPs and meetings for healthcare professionals and caregivers. These meetings cover practical issues for looking after cancer patients. The MRL also organises doctor-patient meetings and conferences on patients' rights. The 43 national cancer organisations are involved with the organisation of these meetings/courses.
- A good place to access information is the Internet. The number of Internet users in Hungary is not as high as in some other European countries, but more than 50% of cancer patients (or their relatives) get information from the Internet. One of the roles of the MRL is to advise on reliable and accurate sources of Internet information.
- The MRL operates cancer help-lines in some major cities such as Budapest, works with the media (radio, TV, newspapers), and produces leaflets and booklets for some cancers (breast, lung, liver, kidney, prostate, skin, gynaecological). The MRL also assists with the follow-up and rehabilitation of cancer patients.
- Patient support groups are good places to meet others with the same condition for mutual support. The MRL runs a number of patient support groups for cancer patients and their families. The kidney cancer patient support group has been running for 2.5 years. During the meetings there are lectures about common problems like access to new medicines, side effects of drugs, the financial problems accessing new drugs, alternative medicines, the role of body and soul in cancer, etc.

Jolan finished her presentation by suggesting that people have twice yearly ultrasound scans to screen for asymptomatic tumours in the liver, kidney, ovary, pancreas, etc. This procedure is inexpensive, not painful, and has no side effects.



### CancerCare Connect Education Workshops (USA)

Rosalie Canosa, Director of Programs, introduced CancerCare (U.S.). Her presentation concentrated on CancerCare's education workshops for patients, their families and caregivers as a means to disseminate good quality, accurate information about kidney cancer and its treatments in a form that is easily understood.

From the point of diagnosis, cancer patients and their families are faced with a variety of treatment and supportive care choices and decisions. The need for credible information in a short period of time is a major psychosocial crisis for patients and their caregivers.

There are a number of barriers to effective onsite, face-to-face educational programmes for cancer patients, such as: fatigue, limitations in physical mobility, living in remote, isolated, rural locations or communities; busy life styles; travel costs; time constraints and issues with childcare and caregivers.

CancerCare's free Connect Education Workshops are a way for people to learn about cancer-related issues from the convenience of their home or office. Leading experts in oncology (including experts in kidney cancer) provide the most up-to-date information on the telephone. These are interactive educational programmes to help patients and their families better understand and cope with diagnosis, treatment options, quality-of-life concerns, treatment side effects, pain management, doctor-patient communication and other important topics.

The workshops are conducted through the use of teleconferencing technology, and an expert leads each workshop. There are dynamic and interactive question and answer sessions and live streaming of the workshop in webcasts on the Internet. The workshops are also available as podcasts and telephone replays after the event for those who missed the live event. To date, there have been 53 workshops with 51,000 participants, involving 150 faculty members and 130 partner institutions, covering 50 US states and territories and accessed by 59 countries.

CancerCare has used technology in an innovative way for the workshops; teleconferences and podcasts are ideal methods to overcome geographic barriers to educational interventions and the technology offers rapid dissemination of evidence-based treatment, supportive care and clinical trial information in rural communities.

Telephone education workshops are weekly, hour-long, interactive programmes conducted over the telephone. All workshops involve an expert faculty, such as an oncologist, and collaborating organisations. The workshops average 500-2,500 participants per live call and CancerCare has a unique partnership with the teleconference vendor that enables the workshops to take place.

Archives of podcasts of the telephone workshops are available on the CancerCare website: [www.cancer.org/podcasts](http://www.cancer.org/podcasts).

They are also available as real audio streaming, MP3 or iPod downloads and telephone replay, 24 hours a day, 7 days a week (1-888-337-7533).

The following are some comments from patients about the workshops they participated in:

- "The doctors presented the information in a very thorough, organised way at a good level for me, in layman's language. What a great way for those of us who live in more isolated areas to learn without travelling great distances."
- "I live 280 miles round trip from my oncologist. These teleconferences are my connection to a wider community. I am rural and isolated."
- "Out in rural areas we don't always have the quality of care that patients receive in cancer centres and larger cities, so the information we are able to get is invaluable. This was very informative. I learned several things that were new. Keep these workshops coming!"

Rosalie concluded her presentation by summarising the lessons learned from running the workshops. These telephone education workshops and podcasts have overcome the many geographic, travel, logistic, cost, access and fatigue barriers that have historically precluded many patients' participation in workshops. Participants mentioned that the workshops gave them hope, they were in layman's language and easy to understand, gave good access to knowledge, were compassionate and participants felt that they were not alone in their cancer journey.



### Lithuanian Rare Cancer Patients Advocacy Group (ROLLD)

Dovile Janulynaite spoke about the work of the Lithuanian Rare Cancers Patients Advocacy Group (ROLLD), founded in 2009. Today there are more than 150 members, including rare cancer patients, their family members, doctors, and all who are touched by rare cancers.

ROLLD provides a patient advocacy service, organises member meetings and conducts consultations. ROLLD is a member of many international cancer patient organisations. Kristina Andrekute represents the group in the ECPC (European Cancer Patient Coalition) and is the Chair of ECPC Rare Cancer Action Group. More information about the group's activities can be found at [www.rolld.lt](http://www.rolld.lt). Dovile is an active member of ROLLD, a medical student and a Hodgkin's lymphoma survivor. Her vision is to share her experience and knowledge with others.

ROLLD's mission is to represent its members' interests; provide information about the disease and latest treatments; provide psychological support to families and patients; reduce social exclusion; promote volunteering in oncology; and develop literacy in public health preservation.

ROLLD's vision is for patients to feel safe, understood and important. ROLLD wants to be perceived as an understanding friend for patients and their families and an authoritative and recognised partner in health care institutions and public authorities.

According to Lithuanian Cancer Registry, there were 660 patients diagnosed with RCC in 2009. Treatment options include radical nephrectomy with complete removal of the tumour-bearing kidney with perirenal fat and other tissues, which is curative for early stage disease. For advanced disease, new drugs are bought centrally and due to the small number of RCC patients in Lithuania, the doctors have to 'play God' and decide which patients will receive the new drugs and which will not. First-line treatment is interferon and second-line treatment is bevacizumab, sunitinib, or temsirolimus.

Dovile concluded her presentation with a short video on ROLLD's project to bring awareness of the cancer experience within the context of Lithuanian culture and everyday life.

## Situation/role of patients/caregivers:

- Basic knowledge of clinical trials is poor among patients
- Also, knowledge about the investigational drug for the disease is poor
- The meaning of the different phases of trials is unknown
- Personal decision, but sometimes patients feel pushed by their doctors
- Or doctors don't inform patients about trials – because they might lose
- their patients to a trial centre (an expert)
- Sometimes trial participation is motivated only by getting the drug – due to lack of funding of the drugs in their country
- General fear of research/trials (the guinea pig stigma)
- There is a high need to get ALL information regarding the trial
- Sometimes patients in a clinical trial don't know that they are on a trial (e.g. India)
- Only 5% of patients enrol in a clinical trial after the trial is explained (India)
- Some countries: Wealthy/educated people often seek out trials to get best standard of care
- Most of the time the medical and legal language in the consent form is too complicated – for most patients it is not understandable
- It is a challenge to get people to think of trials as the first treatment (as opposed to a 'last option'). Very often patients are already on a standard therapy when they get the trial info.
- In many countries - NO clinical trials are available.
- So "access across borders" is an issue. But who is taking care of the expenses? What about language barriers/issues?
- Often patients do not qualify for trials due to pre/treatment etc.
- The right trial design is important – due to reality. Technology is needed to support the patient/caregiver in the trial (ipad/iphone to track and trace how the patient is doing etc.)
- Follow up after the trial: Why are experts/pharmas never asking for the "customer experience/satisfaction/feedback" in or after a trial?
- Difficulties in finding trials. For many patients [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is not the right tool to find, to understand and to evaluate trials
- Patients must be informed that trials could have benefits and risks: that there is no guarantee that the new agent will work as well as standard treatments, and that they are allowed to leave the trial
- Placebo trials in advanced cancer are unethical and should be avoided.
- They also have an invalid scientific value – because patients are clever: They know very soon - whether they are on the drug or on a placebo (e.g. taste, side effects, communication among the patient-community...)

## Current and future role of patient advocacy groups

### Role of information provider:

- Basic knowledge on drug development and clinical trials: material, training, presentations etc.
- What are the chances, risks, duties, and rights of patients in trials?
- Trials are part of treatment & care – especially in rare cancers
- Providing information on upcoming and current trials (e.g. our own patient-friendly registry database on the website)
- Information: Who are the investigators, who to contact?
- Make important parameters of the trial understandable
- Providing information on the results of a trial
- If specific trials are available: Inform patients with a specific subtype or specific conditions
- Support recruitment of trials – but don't recommend participation in a specific trial.
- Participation in a trial is a decision between patient and experts. It is not a task of a patient group to "sell" or accrue for trials or to push patients into a trial
- Providing information is a sensitive task that has to be done responsibly e.g. to protect patients, patient groups need to deliver objective and independent information at the right time. They should not be seen to "promote" results too early, or distribute overstated forms of communication whether from industry, personal anecdote, or other biased sources.

### Informed Consent:

- Patient groups are/could be increasingly consulted as reviewers/advisers of informed consent to the pharma-companies and the experts. They also can argue to "ethics committees" as patient voice representatives.

### Funding:

- Some patient groups are able to raise money for research projects or finance independent trials

### Future Roles:

- There is a changing role – not to be only the subject of research – but patient groups being involved as early as possible in the clinical research at the design stage
- Depending on the objectives, the knowledge and the experience of a group
- Patient involvement on an international level will be done by international networks/umbrella organisations
- Imaginable: Patient groups as co-researchers or driving forces
- Advocacy for a better research environment – for better regulations.
- Research criteria/endpoints are different from HTA evaluation criteria
- How close to reality is research: e.g., trial selection/bias, validity of endpoints?
- Improving the methodology of trials especially in rare cancers
- Promoting trial access across borders
- Looking to the centres/investigators of a trial: Sometimes trial centres do not reflect real expertise in kidney cancer. Patient groups normally know who the real experts are and which trial centres offer expert kidney cancer care.

- In many countries there is a lack of information from the medical team to the patient. (e.g. In India patients are not usually told how long to continue with meds such as Sutent. After some time they just stop and go to herbal medicines).
- Patients are missing the information that it is continuous therapy.
- Feedback from patients is needed as some patients reduce doses (under-dosing).
- Very often: Side effect management is left to the family doctor / general practitioner. Unfortunately they have no idea about the disease, the treatment and side effect management. UK is giving full record to both the centres and the family doctors.
- General practitioners might just panic and tell the patient to stop the drug.
- Very interesting comparison: If you are a pilot you need a special certification to fly a special type of aircraft. If you are a doctor in most countries around the world you can simply prescribe a therapy. Maybe an unusual approach: oncologists, urologists should be only able to prescribe these types of drugs with a special training-certificate.
- US: three reasons why people stop taking their medicine:
  - - Do not know why they are taking the meds
  - - Being afraid of the drugs and side-effects
  - - Could not afford to buy the drugs
  - - Many problems are based on
    - ▶ lack of expertise and experience of the physicians
    - ▶ lack of communication, support and maintenance

### That's where patient groups should join in to improve adherence.

- In Australia: sometimes specialists are trying to explain but patients only take in 15%. Lack of communication between doctors and patients as lack of time.
- "Practice/Oncology/Therapy nurses" should be taught to help patients in these first steps and to also link people to patient groups. Unfortunately in many countries these nurses are not available or less available in the system.
- In Canada "nurse care managers" are available that help you along, giving advice on drugs and when to see the experts, etc.
- Putting too much burden on patient – doctors often do not follow up
- Special services where people can meet and talk about side-effects are needed, either virtual (internet) or in real life
- US: multi-systemic type of approach is necessary – change of reimbursement if hospitals do not follow up!
- Use of toll-free advice lines e.g. from patient groups or pharmaceutical companies. Patients are sometimes reluctant to "bother" their doctors, so it may help to have a person from a care-centre gives advice via telephone
- Packaging should be adapted e.g. like contraceptives marked with days, days off etc.
- Nutrition, dietary issues, drug interactions are linked to this issue
- Complementary meds and herbal meds: use/dangers should be explained
- "Doctor's compliance", dosage modifications, taking off and on meds – doctors change schedule without really knowing what effect it will have. This is a topic for real experts!
- Doctors dealing with progression: Some cut off the drug immediately, others look closer at the results, the problems, the solutions.
- What criteria to use in order stop meds: What are real criteria of progression?!
- (For patients stabilization is a great goal, sometimes slow growing progression under a well tolerated therapy.)
- Some people in India or other developing countries or emerging markets do not have enough to eat. Question: Did they eat enough with their meds?
- Multidisciplinary expert approach is absolutely required!
- Important question: What can patient groups do in the field of managing side-effects?
- - Additional question: If they are taking over services – who is paying for this?
- We only concentrate on the current side effects of drugs. What about long-term side effects and the consequences...
- We always argue that these therapies are so expensive for the healthcare systems. How could it be that time/money is not available in the systems to maintain these high investments?
- Patient groups are committed to contribute to this process
- Reimbursement problems are getting more important
- We should start to collect data on side-effects and gather information

**Prof. Dr. Michael B. Atkins**  
**(Absent due to Family Emergency in U.S.)**  
**Deputy Director, Division of Hematology/Oncology**  
**Beth Israel Deaconess Medical Center**  
**Leader, Renal Cancer Program Dana-Farber/Harvard**  
**Cancer Center, Boston, USA**

Dr. Atkins is a graduate of Tufts University and Tufts Medical School and completed a residency in medicine and a fellowship in hematology/oncology at New England Medical Center. He joined the Division of Hematology/Oncology at Beth Israel Deaconess Medical Center in 1997, after ten years at New England Medical Center. In 2002, Dr. Atkins became the Deputy Director of the Hematology/Oncology Division. Dr. Atkins is a cancer clinical investigator and is internationally recognized for his research in melanoma, renal cancer and cytokine-based immunotherapy. He has led some of the pivotal clinical trials in these fields that have influenced the current treatment of patients with melanoma and renal cancer. Dr. Atkins is the Director of the Dana-Farber/Harvard Cancer Center Kidney Cancer Program. He works toward finding treatments, and ultimately a cure, for renal cancer.



**Dr. Sergio Bracarda**

Sergio Bracarda is a Senior Oncologist from Ospedale San Donato, Arezzo/Italy and Contract Professor for the Schools of Specialization in Oncology and Urology at the University of Perugia. Before taking up his current positions, he was first Junior, then Senior Registrar/Consultant Oncologist in the Department of Urology. His main research interests include prostate cancer, metastatic renal cell carcinoma, targeted anticancer therapies and treatment approaches that combine biological agents with chemotherapy. He has written 39 publications in peer-reviewed medical journals, more than 150 abstracts and a number of textbook chapters. He is a member of the American Society of Clinical Oncology (ASCO), the American Association for Cancer Research (AACR), the European Society for Medical Oncology (ESMO) and the European Association of Urology (EAU). Dr. Bracarda graduated in 1986 from the School of Medicine, University of Perugia, and specialized in medical oncology at the Sacred Heart Catholic University of Rome, and in urology at the University of Perugia, where he later became a resident in the Department of Medical Oncology.



**Karen Facey**  
**National Health Technology Assessment Agency, UK**

Karen Facey has been chair of the HTAi Interest Group on Patient/Citizen Involvement in HTA for seven years. She is an independent evidence-based health policy consultant, Non Executive Director of a health provider in Scotland and member of the Scottish Health Technologies Group. She originally worked as a statistician in the pharmaceutical industry and the UK medicines regulatory agency. In the last 12 years she has developed a broader interest in evidence-based decision making in health care. In 2000, she established the first national health technology assessment (HTA) Agency in Scotland, which set up the Scottish Medicines Consortium. Karen has developed a passion to see better engagement of patients in drug development and the HTA process. She was guest editor on a special themed edition of the International Journal of Technology Assessment in Health Care about patient issues and was Chair of the HTAi Policy Forum from 2007-2010.



**Stephen Hindle**  
**Cancer Survivorship Programme Lead, Macmillan Cancer Support, UK**

Steve has worked for Macmillan Cancer Support for the last ten years. His current role is Cancer Survivorship Programme Lead. He leads Macmillan's work about Cancer Survivorship, coordinating activity within the charity, and working closely with partners at DH, NHS Improvement, and National Cancer Action Team, as part of the National Cancer Survivorship Initiative. Previous roles within Macmillan include Head of Service Development, London Anglia South East region; and Macmillan Development Manager, South London and Surrey. Before joining Macmillan he worked as a regional manager for Sargent Cancer Care for Children, prior to its merger to become CLIC Sargent.



**Dr. Purvish Parikh**  
**Medical Oncologist & Hematologist, Managing Director of AmeriCares, Mumbai, India**

Purvish Parikh is an expert in medical oncology and hematology. He joined AmeriCares India in 2008 as Managing Director after an extensive career in medical research. Prior to joining the organization, he served as professor and head of medical oncology at Tata Memorial Hospital for 17 years. Dr. Parikh also founded and served as Director of the Indian Co-operative Oncology Network, a nongovernmental organization.

As Managing Director of AmeriCares India, Dr. Parikh leads gift-in-kind partnerships with India-based pharmaceutical manufacturers and oversees donations to local health care programs in response to natural disasters and chronic resource constraints in underprivileged communities. Dr. Parikh also oversees India-based logistical capabilities, providing AmeriCares with a global distribution hub in India. Dr. Parikh received a medical degree from Bombay University and earned both a Ph.D. and a Master of Business Administration from the University of Mumbai. Dr. Parikh serves as Vice President of the Indian Society of Medical and Pediatric Oncology and is a member of the Indian College of Physicians and the National Board in New Delhi.



**Robert Schaefer**  
**Healthcare communications consultant, ESMO, Berlin, Germany**

Based in Berlin, Germany, Robert Schaefer is an independent international healthcare communications consultant. Over the last 20 years, he has worked for multiple clients, including multilateral organizations, Ministries, government and public institutions, NGOs, patient advocacy groups, professional societies, and industry. Since September 2010, he is the Senior Project Manager of the Rare Cancers Europe multi-stakeholder initiative and runs the partnership's secretariat on behalf of the European Society for Medical Oncology (ESMO).



### **Prof. Michael Staehler**

#### **Leading senior urologist, head of Interdisciplinary Centre for Kidney Tumours, Ludwig-Maximilian- University – Campus Großhadern, Munich, Germany**

Michael Staehler is the head of the Interdisciplinary Centre for Renal Tumors at Ludwig-Maximilians University of Munich, Munich, Germany. Following medical qualification at the University of Munich Medical School and gaining experience in general, vascular and thoracic surgery at both the University of Regensburg, and the University of California in San Francisco, USA, and training in urology at the Free University, Berlin, Germany, he was awarded a PhD for his work on renal cancer at Ludwig-Maximilians University. After joining the Department of Urology, he was appointed Consultant Urologist at Grosshadern Clinics and founded the first Interdisciplinary Centre on Renal Tumors in Germany. Professor Staehler is also head of the Urological Oncology Service for Advanced Genitourinary Cancer and Kidney Surgery and Vice Chairmen of the Department of Urology, University of Munich.

Professor Staehler's main research interest has been the development of novel therapeutics in RCC, particularly in the area of radiation therapy, surgical therapy and novel targeted agents. He is head of the German Society for Immune and Targeted Therapy and member of the Renal Cancer Workgroup of the German Cancer Society. He also serves as a member of

the German Guideline Committee on Renal Cancer, the European Association of Urology Guidelines Committee and is a medical advisor to the German Patient Organization for Kidney Cancer - Das Lebenshaus e.V.. On the editorial board of several journals, Professor Staehler has published more than 70 articles on renal cancer and is a co-author of six textbooks.



### **Dr. Cora Sternberg**

#### **Chief of Medical Oncology, San Camillo and Forlanini Hospitals in Rome, Italy**

Dr. Cora N. Sternberg is a graduate of the University of Pennsylvania School Medicine in Philadelphia, PA and is specialized in both Internal Medicine and Medical Oncology. She is currently the Chief of Medical Oncology at the San Camillo and Forlanini Hospitals in Rome, Italy. Dr. Sternberg completed her fellowship and was later a staff member at Memorial Sloan-Kettering Cancer Center in New York. She has been elected to the prestigious position of Board Member of the European Organization for the Research and Treatment of Cancer

(EORTC). She is Consultant at the Lahey Clinic and holds the position of Adjunct Professor of Medicine in the Department of Medicine, at Tuft's University School of Medicine, in Boston, Massachusetts. She is a faculty member of the European Society of Medical Oncology (ESMO), of the European School of Oncology (ESO), and of the European School of Urology (ESU) of the European Association of Urology. Dr. Sternberg has a great deal of expertise in the treatment of many types of solid tumors and has achieved international recognition for this experience. Dr. Sternberg is on the editorial board and is a reviewer for several international scientific journals, and is an invited speaker at innumerable international meetings. She is a lead investigator on many international research grants, has published more than 150 articles and 50 chapters in peer-reviewed journals and books, and is an advocate of patients' rights and education.

**IKCC Expanding Circles 2012 Conference Co-Chairs:**

**Markus Wartenberg**  
**Das Lebenshaus e.V. (Germany) GIST – Sarcomas – Kidney Cancer**

I am the executive director/spokesperson of the patient advocacy organization Das Lebenshaus e.V./Assoc. I am responsible for conceiving and organizing all community activities with a small team of patients, employees and freelancers. After my commercial education in the industry, I completed my studies as a specialist in journalism & communication. I worked in several different German communication and PR-agencies as a consultant and creative director for national and international brands. In 1993 I founded my own agency, which had a focus on pharmaceutical, medical and health communication. After 10 years within this business, I left the agency in 2003 to manage Das Lebenshaus and Das Wissenshaus.  
 Wartenberg@lebenshauspost.org



**Deborah Maskens,**  
**Kidney Cancer Canada/Association canadienne du cancer du rein (Canada)**

I am the chair and co-founder of Kidney Cancer Canada/ Association canadienne du cancer du rein. I was diagnosed with papillary renal cell carcinoma in 1974 at the age of 14. Back in 1974, very little was known about kidney cancer. I was given a 50/50 chance of surviving the next 5 years. I have survived 37 years so far (the last 15 of them at Stage IV). I have learned to be my own best advocate by learning everything I can about renal cell carcinoma and treatment options. I co-founded Kidney Cancer Canada in 2006 with a fellow patient, Tony Clark, who died in 2010. Kidney Cancer Canada serves over 1500 patients and caregivers across Canada in both official languages (English and French).  
 DebMaskens@kidneycancercanada.ca



## Steering Committee Members



### Jay Bitkower

#### Action to Cure Kidney Cancer (USA)

In late 2000, I was diagnosed with kidney cancer, but fortunately it had not spread and has not recurred. After treatment, I began to do research and attend conferences and lectures about the disease. I soon found out that, although kidney cancer is the eighth most common cancer in the US, kidney cancer is seriously underfunded as compared to other cancers. Therefore, in 2003, I founded an organization which later became Action to Cure Kidney Cancer (ACKC), whose primary objective is to increase the funding for kidney cancer research.

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### Berit Eberhardt

#### Das Lebenshaus e.V. (Germany) GIST – Sarcomas – Kidney Cancer

In the course of the kidney cancer diagnosis of my boyfriend, I read and learned a lot about the disease and its therapy – with the help of Das Lebenshaus. Half a year after his death I founded a patient support group in Berlin – 2 months after that I became manager for Kidney Cancer at Das Lebenshaus e.V. My knowledge about kidney cancer got strengthened by numerous trainings and seminars, attendance at medical meetings and working closely with kidney cancer specialists – needless to say the great Kidney-ONC List and the IKCC colleagues. In my fight against kidney cancer, I am in constant communication with interdisciplinary experts and support patients and their families by competent and active communication of information.

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### Gilles Frydman

#### ACOR – Association of Cancer Online Resources (USA)

- **Founder of ACOR (1995)**
- **Co-founder Society for Participatory Medicine (2008)**
- **Former president SPM (2010)**
- **Member, Editorial Board, Journal of Participatory Medicine (2008- Present)**
- **Consultant, Google Health (2009)**

I am a frequent presenter about the extraordinary power of the internet to help connect large number of patients suffering from rare diseases and help them obtain optimal care.

I created the KIDNEY-ONC list with my friends Steve Dunn and Robin Martinez when the internet was still in its infancy. When the group reached 50 members, Steve thought we would never reach 100. Today we have just under 1,800 members! I am currently working to add many new services to the communities we manage.

[grydman@acor.org](mailto:grydman@acor.org)



### Rachel Giles

#### Von Hippel-Lindau Organization (NL) / Waterloop (NL)

I am a staff/faculty member of Internal Medicine at the University Medical Center Utrecht. I come from a family with an inherited tumor syndrome and have been active in advocacy for patients with inherited kidney cancer since 2003. I run a research lab that is dedicated to understanding how kidney cells are regulated and what goes wrong in the very early steps of kidney cancer. I have been chair of the Dutch VHL Organization since 2009, and an international contact point for Waterloop since 2010.  
r.giles@umcutrecht.nl



### Robin Martinez

#### Kidney-Onc mailing list (one of ACOR's many cancer list-servs)

Robin has been list owner of the Kidney-Onc mailing list since 1997 and list owner of Papillary-RCC and Chromophobe-RCC since they were founded. Her husband died from metastatic kidney cancer in 1998, nearly 10 years from his initial terminal diagnosis.  
robinjoker@aol.com



### Vandana Gupta

#### V-Care Foundation (India)

Diagnosed with Hodgkins Lymphoma in 1993. There was a lack of information and emotional support at that time. This motivated me to start V Care. Over the years we have got patients of various types of cancers and are now also involved with kidney cancer in a big way.  
vcare24@gmail.com



### Andy Thomas

#### Kidney Cancer Resource (U.K.)

I was diagnosed with kidney cancer in 2007. I am an IT professional of some 24 years largely within investment banking but recently changed my focus and am a chief information officer within the UK's National Health Service. Outside of the NHS I have created a number of patient-led kidney cancer related web-sites and also helped lead and drive fundraising activities. I now act as the web-master for IKCC.  
andy.thomas@taffdirect.com



**Andrew Wilson**  
**Rarer Cancers Foundation (U.K.)**

I am the Chief Executive of the RCF and have been in post since 2008. I am responsible for the overall development of the charity and engage and advise policymakers and government on a regular basis to effect change for cancer services and improved care for patients.

- I am a member of the All Party Parliamentary Group for cancer.
- Steering group member of the Cancer Campaigning Group
- Founding and steering group member of IKCC
- CEO of the Hepatitis B Foundation (UK)

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**Rose Woodward**  
**Kidney Cancer Support Network (U.K.)**

I am a survivor of kidney cancer. I was diagnosed in 2002 and underwent a radical nephrectomy in the UK and 5 years follow-up. I live in beautiful Cornwall in the far southwest of England. I am a passionate advocate for patient rights and patient involvement in healthcare especially, of course, for kidney cancer patients. I founded the Kidney Cancer Support Network in 2006 because I believe patients have a stronger voice when we work together and I support any project which aims to empower patients. I am proud to be a founding member of IKCC and pleased to be working to help improve the lives of kidney cancer patients wherever they live.

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It is the responsibility of the individual kidney cancer patient to discuss any issues raised in this report with the doctor treating him. The information contained in this conference report should, under no circumstances, be viewed as a replacement for individual consultation or treatment by specialist oncologists or urologists. The contents cannot and must not be used for self-diagnosis or self-treatment.

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# EXPANDING CIRCLES

in Supporting Kidney Cancer

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