

EXPANDING CIRCLES

in Supporting Kidney Cancer

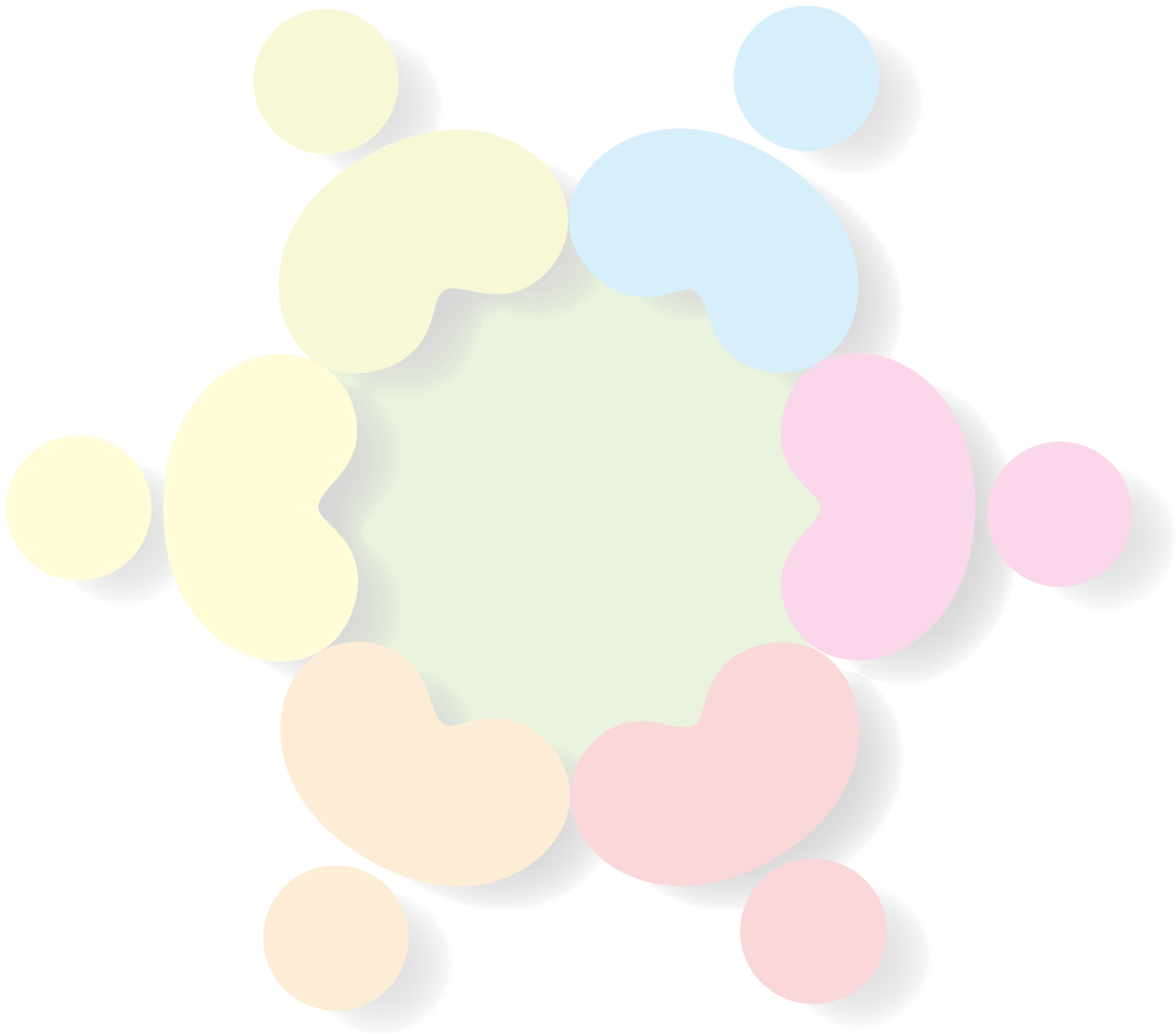


International
Kidney Cancer
Coalition

**3rd International Conference for
Organizations Representing Patients
with Kidney Cancer
April 11 – 13 2013 in Windsor, UK**



Conference Report



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“I am very happy to have had the chance to participate, which allowed me to meet and interact with people like me affected by kidney cancer and share ideas and solutions to improve our work.”

Nathalie Bedu, A.R.T.u.R (France)

Acknowledgement

We would like to thank the following funders who supported the 3rd 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 3rd IKCC Conference in Windsor, UK.

The idea, conception, planning, preparation, realisation, management and the summary of the EXPANDING CIRCLES 2013 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:

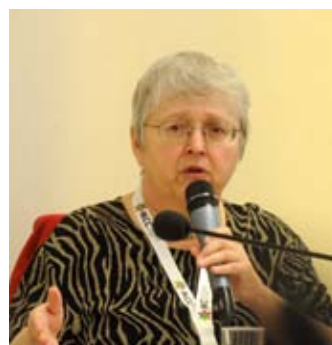
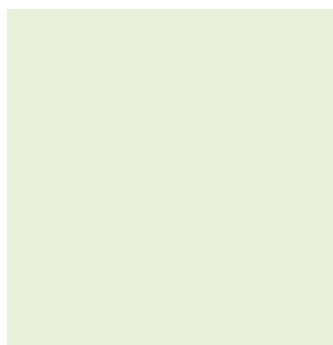
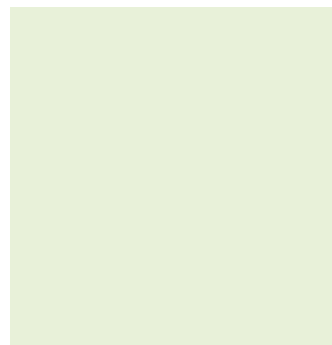
IKCC welcomes donations, grants and sponsorship to fund certain projects and to allow our network to grow and develop. IKCC has developed a transparent and robust Code of Conduct to guide the relations between patient organisations and the industry (including their representatives and consultants). Please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



**Day 1 -
Thursday,
11th April
2013**

An introduction to Kidney Cancer –
especially for newcomers
or those needing a refresher

- Moderator: Dr Rachel Giles (Netherlands)
- Dr Georgios Kallinikas (Greece)
- Robin Martinez (USA)



10:00 -12:00

Optional Pre-Meeting: Kidney Cancer 101

Kidney cancer is often overlooked as a major cancer although it ranks among or near the top ten worldwide and is increasing in frequency. We are fortunate that research is making great strides in treating renal cell carcinoma (RCC). Patients with advanced disease are living longer than ever before. However, as we increase our knowledge it becomes clear there is very much more to discover.

For example, the most common type of kidney cancer known as clear cell renal cell carcinoma (ccRCC) has been considered a single subtype of kidney cancer until recently. We now know this type of RCC has at least three subtypes itself! Previously unknown genetic syndromes have been discovered with only a few patients and as yet have not even been named. As our tools for research improve, it is clear we have only begun to unravel this mysterious disease.

Kidney Cancer 101 has been a popular feature of all three IKCC conferences. In this session we go over the basics of the disease. Researcher Rachel Giles presented an overview of kidney cancer and its current drug treatments, patient activist Robin Martinez talked about drug side effects and how to alleviate them, and urologist Georgios Kallinikas discussed different surgical options. This is in preparation for much deeper discussions to come during the conference itself.

Welcome and Opening Remarks

- Rose Woodward (UK)
- Markus Wartenberg (Germany)



13:15 - 13:30

Welcome, Opening Remarks and Organisational Issues

Our third IKCC conference opened with a warm welcome to England by Rose Woodward, a native who lives in Cornwall. The history surrounding us was evident as was the charm of the convention's venue in Windsor, a sprawling estate that had served many purposes before becoming a conference hotel.

Markus Wartenberg continued the welcoming remarks with a brief discussion of the past and future of the International Kidney Cancer Coalition (IKCC). Our global network of kidney cancer organisations is growing, and yet remains true to its original values of open, democratic, collaboration between national patient organizations who have a specific interest in kidney cancer. Since our first conference in Frankfurt in 2010, we have helped new kidney cancer groups develop, and have strengthened the focus on kidney cancer in cancer and kidney health organizations across many continents.

IKCC looks forward to continued progress, growth, and collaborative projects with organisations around the world. Among our goals are greater awareness of kidney cancer worldwide, greater international collaboration across patient organisations, and access to quality surgical and medical treatment for patients everywhere.

- Kathy Oliver (UK),
International Brain Tumor Alliance (IBTA)



13:30 - 14:00

Keynote: Perspectives from Other Cancer-Specific International Coalitions

A young coalition like IKCC can learn a lot from the experiences and challenges of other global networks and the solutions they develop. This year's conference started with an inspirational keynote speech from Kathy Oliver, co-director of IBTA, the International Brain Tumour Alliance. The courage and determination of Kathy's son Colin from his diagnosis with a brain tumour at age 24 until his death at age 32 provided Kathy with the driving force and inspiration for her involvement with IBTA and the wider cancer community.

IBTA is a worldwide cooperative initiative that advocates for equitable patient access to therapies, encourages the establishment of support groups in countries where they don't yet exist, and raises awareness of the challenges of this devastating disease. Almost 200 brain-tumour and cancer-related organisations worldwide support IBTA's annual awareness initiatives, International Brain Tumour Awareness Week and Walk Around the World for Brain Tumours. The work and proceeds remain local to each country. However, the increased global awareness helps patients everywhere. Each year IBTA also publishes 12,000 copies of Brain Tumour, a major magazine distributed free in 109 countries.

IBTA's achievements are impressive, and it was interesting to see that the challenges we face are so similar. Conference participants felt we might collaborate with other networks across indications, developing common projects to deal with challenges faced by all our groups. In this way we can increase our impact despite each group's limited numbers and finances.

- Sandra Collette, EORTC (Belgium)
- Moderator: Markus Wartenberg (Germany)



14:00 - 15:30

Understanding Cancer Clinical Trials

Sandra Colette is a member of the staff of the European Organisation for Research and Treatment of Cancer (EORTC). Her 90-minute presentation provided background on why we need clinical trials and how to understand the language and methodology of clinical research.

The first part covered basics including what a clinical trial is; the role of patients; the stakeholders of clinical trials; the objectives and endpoints of clinical trials; the four phases of clinical trials and what each aims to achieve; and definitions of terms like bias, randomization, and data monitoring.

The second part was aimed more directly at experienced patient advocates. Topics included statistics in clinical trials, hypothesis testing, and decision-making. Terms such as p-value, sample size, and the Kaplan-Meier curve were explained.

Note: IKCC is collaborating with EORTC and other international advocacy groups to develop a more in-depth two-day training course on “Understanding the Basics of Clinical Research.”

- Prof. Charles Swanton (UK)
on mutations, biomarkers, and metastatic tumor profiling
- Dr. Janice Dutcher (USA)
on the future of targeted therapy and the role of immunotherapy
- Moderator: Dr. Rachel Giles (Netherlands)



16:00 - 17:30

Personalized Medicine and the Future of Kidney Cancer Treatment

Both speakers were medical oncologists specializing in kidney cancer.

In Prof. Swanton's next-generation sequencing of 10 clear cell RCCs and their associated metastases, his analysis concluded that while RCC is unique in having primarily a single driver of mutation (VHL) for a relatively long period of time, metastases eventually evolve clonal outgrowths which show considerably more heterogeneity – differences in their mutations. He compared this process to trees whose trunks reach varying lengths before branching. At the point of branching, consequent diversity occurs in underlying genetic makeup and in drug sensitivity. Genetic variation within and between tumours reflects the natural course of disease. Understanding the mutational spectrum present in an individual patient with quicker and more cost-effective technology will improve treatment.

Dr. Dutcher went on to review the current status of available drugs as well as several in the pipeline. Cabozantinib, now in global trials, is a promising VEGF +cMET inhibitor with apparent effect on bone metastases, which is unusual and exciting. In addition, several TKIs currently in the pipeline appear to have reduced toxicity profiles compared to those already approved. Moreover, for patients with limited metastatic disease, immunotherapy with either high-dose IL2 or experimental anti-PD-1 antibody still has potential within the treatment regimen to be curative. Selection of eligible patients can improve the success rate.

Impressions of the Conference Welcome Dinner at The Chapel, Beaumont Estate





**Day 2 -
Friday,
12th April
2013**

- Moderators: Robin Martinez (USA) and Markus Wartenberg (Germany)



07:30 – 08:30

Early Breakfast Session

Clinical Trials 101: An Introduction

Optional early breakfast sessions were a new item at this year's conference. The breakfast session on early Friday morning was moderated by Robin Martinez (USA) and Markus Wartenberg (Germany). This session was about clinical trials, building on the base of information provided by our earlier speakers. Participants increased their understanding of the field of clinical research through questions and discussion with one another and the moderators, who each have a great deal of experience in this area.



09:00 – 10:30 Marketplace Sessions

Another new feature of this year's conference was the marketplace session. Attendees moved from room to room, choosing to discuss any three of the five discussions offered.

Communications: Website/social media **Andy Thomas (UK)**

The general message to patient organisations was to keep their websites simple in the early stages and not overspend on detail until the direction of the organisation is fully understood. Users will dictate what they want to engage in. Think of sites like Google that offer a very simple interface and do one thing but do it really well. Simplicity and not complexity is the art of stickiness (making the user want to stay longer using the website). Open source tools such as Joomla, Drupal or Wordpress are good "start up platforms" for new patient organisations.

Regarding IKCC, the general consensus was that our website should be an international portal where organisations can put in simple bios and links rather than a forum. Providing trusted information is the key.

Working with medical experts; how to talk with medical professionals

Dr. Rachel Giles (Netherlands)

If the individuals representing a patient organisation have no health-related job experience or specialized education, one of the biggest challenges they face is getting a foot in the door to talk with relevant medical professionals. It is worth some extra effort to develop your abilities since medical professionals can

- (1) be your organisation's most immediate source of information;**
- (2) help coordinate regional resources as well as patient access to services; and**
- (3) serve as medical advisors for your organisation.**

You can meet your country's top medical professionals by attending their professional society gatherings like the National Society for Medical Oncologists. Identify individuals who will actually help you (e. g. specialists in training, residents, and interns can gain prestige from this) and appeal to their sense of generosity. With highly respected professors, realistically don't expect much from them beyond the use of their name. Be respectful and require as little time as possible. Know what you are talking about before approaching them. Follow up with regular feedback on how they have contributed (for example, your newsletter). Sometimes you might need to explain the added value of your patient organisation to overall care. Be gently persistent. Continue to add to your own education and stay up to date on medical developments.

Working with industry: do's and don'ts, grant requests

Deb Maskens (Canada)

Funding from pharmaceutical companies allows you to reach more patients and provide more programs and services. However, you must be transparent, balanced, and multi-sponsored; treat sponsors equally; and have a clear code of conduct. You do not want government, media, the public, and other organisations to view your group as biased.

Present your organisation as offering more than a charitable opportunity. Propose substantive projects and patient conferences as well as fundraising events. Build a partnership based on where your interests overlap; be aware of where they do not. Build strong, ongoing relationships at medical conferences and events. Share updates and show your progress.

Define your group's boundaries in advance: what proposals would you say "no" to? Remember you're not there to sell anything to or from your members. As a patient organisation, you set the terms of engagement. At all costs, protect your organisation's integrity and your members' privacy (their data).

The administrative burden on your group can be significant. Each pharmaceutical company has its own grant application processes, contracts, and follow-up requirements. Industry's granting of funds is often limited to a one-year basis, making long-range planning difficult.

Another challenge is that company personnel change constantly so you are always starting over with a new person who may have no background or experience in kidney cancer. Provide one point of contact in your group. Deal with one person at each company, developing a professional relationship. Often companies have someone whose title (e.g., Stakeholder Relations) reflects this sole role. If you must deal with a brand or marketing manager, be careful of potential conflicts.

Principles of patient support

Rose Woodward (UK) and Robin Martinez (USA)

Patients and caregivers are experts about living with kidney cancer. Their experience and insights are unique and valuable. Patient support is intellectually challenging and emotionally draining. To be able to do the work effectively, develop a group of people to share the load.

Aim to build up a library of resources. Try always to back up any advice or information with good solid evidence. It is important to be a listening ear as well as a provider of information.

The best patient support may mean re-directing patient queries to the most appropriate place. Different organisations provide different types of support. It is important to decide what areas you will work in. For example, will you campaign for change, be a clinician-led group or a patient-led group, stick to support or offer medical information?

Different mechanisms can provide different types of support, such as telephone helplines, internet forums, social networking online, email listservs, one-to-one individual advocacy, support group meetings, regional or national patient information days, "ask a nurse" service, buddy or mentor programs, a library of books, leaflets, and videos, etc.

Most participants in this session agreed communicating with someone else who really understands what you are going through can be inspirational. Providing quality patient-support services often is life-changing, both for those receiving the support and those providing it.

How to grow your group: patient days/meetings

Markus Wartenberg, Berit Eberhardt (Germany)

One major responsibility of a kidney cancer advocacy group is to provide informational and emotional support to help their members cope with their new, uncertain, stressful, and life-changing situation. As a platform for this learning and sharing, patient groups organize meetings bringing patients and caregivers together along with eminent medical experts to share their expertise with the eager audience.

Patient meetings are important to support patients and caregivers - but they are also a way for a patient group to get publicity and build a positive image. Over time, many of the patients and their families will be able to bond with each other to bring a tremendous amount of comfort and solace into their lives. Bringing patients together helps also to identify active and interested members who could become valuable and engaged volunteers for your group.

The session discussed pointers on how to organize and conduct such meetings:

- Some examples of patient meetings are local, regional, or national; educational seminars, social events, or a combination of the two
- What are your objectives in running such a meeting?
- Beside presentations, what sort of session formats work? How can you create interaction?
- What content to consider for presentations, e.g. from medical experts?
- Best practices and tips to plan, organize, run, and follow up a patient meeting

- Dr. Michael Jewett (Canada)
- Prof. Borje Ljungberg (Sweden)
- Moderator: Rachel Giles (Netherlands)



11:00 – 12:30

Kidney Cancer Guidelines from Around the World

Dr. Michael Jewett, a Professor of Surgery (Urology) at the University of Toronto, reminded us that guidelines are “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.” At this time, clinicians are the principal users of guidelines, but patients are increasingly referencing guidelines for follow-up and treatment decisions to ensure consistency and quality of care. One area still requiring evidence-based data is a kidney cancer follow-up protocol with evidence to support a recommended interval and modality of screening for each stage of disease. Professor Jewett remarked it would be enormously helpful if the reason for scanning (because of symptoms or because of scheduled follow-up) were noted when recurrence is found.

Prof. Borje Ljungberg, a urologist at Sweden’s Umeå University, presented his recent European Urological Association (EAU) 2013 Guidelines. Although they already represent years of work, they still require much tailoring because relatively few studies met their stringent criteria. The guidelines stipulate currently supported first-line, second-line, and even third-line treatment options. Importantly, these are evidence-based, although not legally binding.

A lively 35-minute discussion followed these presentations including cultural comparisons of guideline applications as well as the value of patient input in the next revision of the EAU patient guidelines.

- Robin Martinez (USA)
on current practice and patient experiences
- Dr. Michael Jewett (Canada)
on early stage and advanced stage
survivorship and kidney cancer
survivorship care plans
- Moderator: Deb Maskens (Canada)



14:00 – 15:30

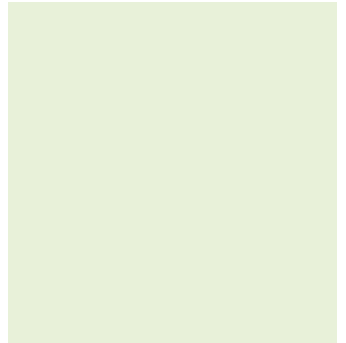
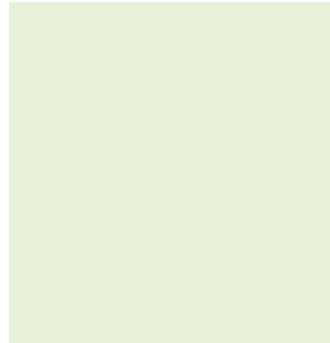
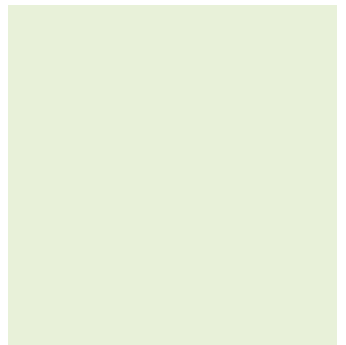
Kidney Cancer Survivorship – Issues and Opportunities

This session began with a question to patients and advocates in the audience: "What information were you given about your kidney cancer at the time of diagnosis?" The varied results revealed a strong need for better patient information about living with and beyond a diagnosis of kidney cancer.

Robin Martinez gave a heartfelt presentation based upon her survey on KIDNEY-ONC, a global listserv. She shared direct quotes from patients and caregivers around the world who emphasized the strongest need is for patients to be seen by an expert in renal cell carcinoma. Patients with early or late-stage renal cell carcinoma have huge information needs across geographic boundaries that are being met by online communities such as KIDNEY-ONC.

Dr. Michael Jewett spoke of the rise of the kidney cancer survivorship movement. He cited a national study by Kidney Cancer Canada that highlighted key communication disconnects between urologists and their patients, with almost all confirming the need for formal survivorship care plans. Research is underway in Canada to develop a tool for patients that will provide customized information regarding stage-specific surveillance plans, possible late-term health outcomes, and evidence-based recommendations for improved survivorship.

- Surgical treatment for bone metastasis, Prof. Dr. Hans Roland Dürr (Germany)
- Radiation and SRS therapies for brain metastasis, Dr. Shyam Kishore Shrivastava (India)
- Moderator: Berit Eberhardt (Germany)



16:00 – 17:30

Localized treatment for bone and brain metastasis in kidney cancer

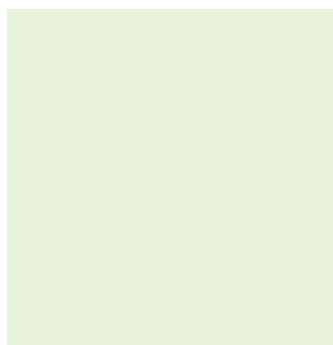
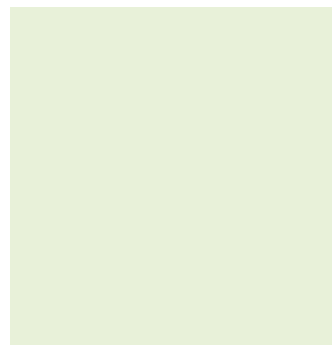
Prof. Roland Dürr's experience suggests that 30% of mrcc patients will experience at least one bone metastasis in the course of their journey. Rather than palliative treatment (often radiation), Prof. Dürr advocated for a new philosophy: for patients and oncologist to first investigate any available option for bone re-section (surgery). (Likely involving a visit to an orthopedic oncologist with the goal of removing the bone lesion completely.)

Dr. Shyam Shrivastava addressed the prevalence of brain metastasis in mrcc patients (under 10%) but focused on changing paradigms for localized treatment focusing on SRS (Stereotactic Radio Surgery) also known as cyberknife or gamma knife. In the past, many patients underwent WBR (whole brain radiation) which can be associated with significant cognitive loss. Overall theme of his talk was to "save the cognition". One delegate to the conference (Clive Stone from UK) indicated that he had had cyberknife to treat 23 brain tumours so far.

Impressions of the External Dinner at Dorney Lake Olympic Park, Windsor



**Day 3 -
Saturday,
13th April
2013**



7:30 – 8:30 Early Breakfast Sessions

The early breakfast on Saturday morning offered two parallel discussion groups on access to expertise and treatment. The one for the western world was moderated by Andy Thomas (UK); the other for emerging markets was chaired by Vandana Gupta (India). This new format was helpful to exchange experiences, to understand more deeply the different challenges, and also to inspire the Steering Committee Members for the future objectives and work of IKCC.

Access to Expertise and Treatment in the Western World **Moderator Andy Thomas**

Clive Stone spoke passionately about how patients in the U.K. got access and how they campaigned in the UK. Delegates from Australia, Finland, Canada/Quebec shared issues and strategies for reimbursement of approved therapies.

Much discussion centred on clinical trials:

- Trials are increasingly being conducted in Eastern Europe.
- Trials need to give us evidence on sequence of treatments.
- Access to trials for rarer subtypes of rcc is increasingly an issue.
- How do we create satellite centres for international trials?

A major takeaway point: IKCC will be engaging with researchers, pharmaceutical companies and approval bodies early in the design and development of clinical trials to better ensure that trials are designed with patient needs in mind.

Access to Expertise and Treatment in the Emerging Markets **Moderator Vandana Gupta**

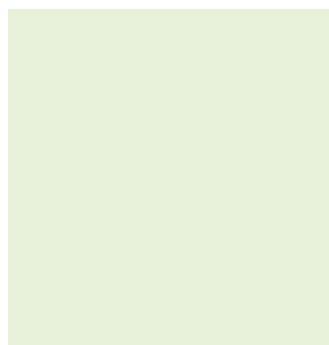
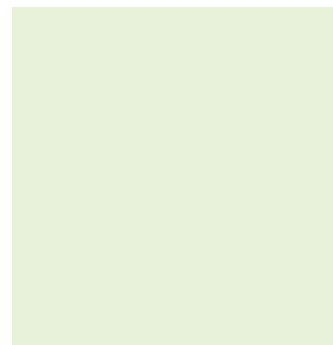
Medical care is usually the last priority for any family struggling to pay for necessities like food, shelter, and clothing.

The major issues are availability, accessibility, affordability, and acceptability of medical treatment. Treatment means going away from home, arranging cash and still not being sure of recovery, and fear of being in unfamiliar surroundings.

Medical services are often far away, there is a long waiting time, and services are inadequate; thus people are reluctant to use them. Added to this are unfriendly staff attitudes and total dependence on the decision of the doctor. People have to pay for services themselves; insurance is nonexistent or inadequate. Patients are insecure and don't talk about their cancer due to the stigma. In some places, government funds for treatment and equipment are diverted by uncaring individuals.

Needed are awareness, education, counseling, community involvement, and participation by support groups and government. The number of quality physicians in the rural areas must be increased.

- Dr. Paul Nathan (UK)
on clear cell
- Dr. Janice Dutcher (USA)
on rare subtypes
- Moderator: Rose Woodward (UK)



9:00 – 10:30

Kidney Cancer Treatment Updates

Dr. Nathan talked about current drug treatments for clear cell patients with metastatic kidney cancer and treatments showing promise for the future. Adjuvant treatment with TKI's (to prevent recurrence in medium to high risk patients) is available only within a clinical trial. Combining drugs, changing regimes, and dose reduction have potential to improve overall survival time, but quality of life is also very important to patients. Doctors and patients need to be pragmatic and take account of evidence before making treatment changes.

Immunotherapy with high-dose Interleukin-2 is showing good response rates in carefully chosen patients in the UK. New generation immunotherapy drugs such as anti-PDL1 and anti-PD1 (nivolumab) are entering late-stage clinical trials and may extend life still further for heavily pre-treated patients. Overall, patients today are living longer than anyone imagined even five years ago.

Kidney cancer patients and advocates must work to ensure that drugs which are clinically effective in early-stage trials are developed and reach the patients who need them. We must rethink the mathematical modeling health economists and regulatory authorities use to calculate the value of life-extending drugs. Dr. Nathan is eager to see leading clinicians work with patient organisations such as IKCC and the pharmaceutical industry to improve access to all clinically effective treatments, as it is in no one's interests to develop drugs that are not reimbursed and therefore unavailable to the patients who need them.

Dr. Janice Dutcher discussed the rare subtypes of RCC whose patients have fewer treatment options compared to clear cell patients. The evidence base for treating them is poor because they usually are excluded from clinical trials due to their rare subtype. Dr. Dutcher feels trial designers could do more to build an evidence base by encouraging rare subtype patients to join trials and then carry out subset analyses.

Treatment options depend a great deal on individual pathologies. In some rare subtypes such as papillary, chromophobe, translocational, and the FH mutation, treatment with TKIs and mTOR inhibitors can give results similar to clear cell patients. In other more aggressive rare subtypes, chemotherapy has been shown to be effective. Clinicians are also watching the newer agents. In particular, Cabozantinib (an anti-VEGFR and anti-MET drug currently in phase 3 clinical trials) on paper looks effective for papillary patients; but in an RCC trial this drug was studied in clear cell patients only. Designing the trial differently with the input of knowledgeable patients could have provided distinct benefits to underserved patients with rare subtypes of RCC.

- Moderator: Vandana Gupta (India)



11:00 – 12:30

Sharing Best Practices in Kidney Cancer Support and Advocacy

Presenters:

Kidney Health Australia

V Care Foundation, India

Stand Up To Cancer Naija, Nigeria

Association GLADIATOR, Poland

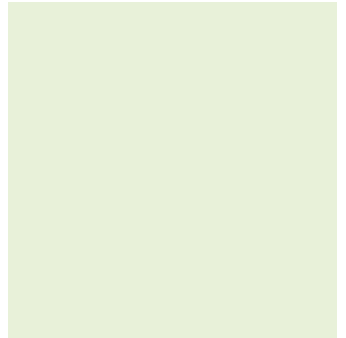
James Whale Fund for Kidney Cancer, UK

ACKC = Association to Cure Kidney Cancer, USA

VHL Family Alliance, USA

This session showcases projects of patient organisations which demonstrate best practices in dealing with kidney cancer. This session allowed us to hear directly from conference participants on what their groups are doing and to get ideas for our own organisations. The variety and scope of projects shows what determined patients can do to improve their own situations – whether in Poland, Nigeria, the U.K, U.S., Australia, or in India. Topics included building up the resource pool, developing relationships with pharmaceutical companies for access programs, organizing galas and parties as fundraising tools, offering peer-to-peer support, and improving the conditions of kidney cancer patients by helping them deal with the financial burdens of treatment.

- Markus Wartenberg (Germany)



13:15 – 14:15

IKCC Projects and Future Direction

This session highlighted the need for earlier and better patient involvement in clinical research to achieve effective cancer treatments more quickly. Patient involvement in cancer clinical research means research done with or by patients rather than doing research for, to, or about them.

Patients and their representatives offer a unique perspective of experiential knowledge acquired by dealing with their condition on a daily basis. They can help create more efficient trials, address issues expressed by those living with the condition, and help solve operational issues and ones that affect recruitment and compliance. Considering these elements in the early stages of trial design saves time and money in the long run. Patient organisations can play a key role.

An innovative IKCC project was briefly presented as an example of collaborative research started by a patient network. The basic initiative was brought up by IKCC. Now EORTC (European Organisation for Research and Treatment in Cancer), UCL London (School of Pharmacy), four leading industry partners and IKCC are developing the study. IKCC identified clearly the need for an international study to highlight practical issues in oral cancer treatment and side effect management in mRCC. In a collaborative study, 750 mRCC European patients would be followed over time to learn more about their situation and come up with future ideas for interventions and support.

- Deb Maskens (Canada)
- Andy Thomas (UK)



14:15 – 14:30

End of Conference, Summary and Closing Remarks

As the conference drew to a close, Deb Maskens thanked all the attendees, speakers, and sponsors and offered brief summarizing remarks. Andy Thomas then presented a humorous look at Britain which ended the conference with appreciative laughter. Participants exchanged personal farewells and left looking forward to ongoing engagement with IKCC and next year's conference.

Windsor 2013: Feedback

Some comments from Emails...

Thank you for the high quality conferences and all the good times spent together. I am very happy to have had the chance to participate, which allowed me to meet and interact with people like me affected by kidney cancer and share ideas and solutions to improve our work volunteers within the association ARTuR but also to help advance the care of patients with kidney cancer in the world, to enjoy the experience of other organisations, and perhaps one day work together.

Thank you again. Warmest regards, Nathalie Bedu, France

It was really a lovely and useful IKCC-meeting at Windsor. So many thanks for your excellent preparations and guidance.

Timo Koponen, Finland

It was very nice to met you in UK and take part in the IKCC Conference. I think it was a great successes. I hope it will be very good push for development activity of protecting rights of people with kidney cancer in my country. Once more thank you for your kind hospitality and support.

Valentyna Ocheretenko, Ukraine

Before all, I must thank you for the fantastic days I had at the IKCC conference and give you my congratulations for the well organised conference. It was the 1st time I attend a kidney cancer organisation and I was very touched by all the presentations and by the testimonies of those who survived an kidney cancer. I had my first APIR board meeting after the conference, where we decided to start working on the creation of a kidney cancer group within our kidney patients association.

Best regards, Paulo Zoio, Portugal

I would like to thank everybody and personally you for everything you have done for the VHL family alliance Greece and me personally.

Best regards, Kallinikas Georgios MD, MSc, Athens - Greece

I write to say thank you for the Conference. I think it was one of the best organised conferences that I have attended. The documentation was really superb, most interesting. It takes no great feat of imagination to realise that a lot of hard work went into producing such an event. So thank you very much indeed.

Best Wishes, Pat Hanlon, KCUK

Some comments from the Evaluation Forms...

**Very inspiring and inspirational.
Thank you for the opportunity to be part of the IKCC**

**Always very rewarding in so many ways.
Great information learning, sharing and
wonderful networking.**

**We heard many useful information that may help us
improve our organisation and better help our patients.**

**Congratulations and thanks for this excellent conference.
I feel myself if I were in a family with other participants.
I hope we shall meet once again.**

Sandra Collette**European Organisation for Research & Treatment of Cancer (EORTC), Belgium**

Sandra Collette received her Master of Science in Public Health Specialty Statistics Applied to Social Science and Public Health, ISPED, Bordeaux, France in 2006. Since 2007 she has been working at the EORTC as fellowship and then as Biostatistician, involved in various EORTC diseases oriented groups. She is now the Biostatistician responsible for the EORTC Imaging Group and work also for the EORTC Genito-Urinary Group and the Radiotherapy Group.

Prof. Dr. Hans Roland Dürr**Head Orthopaedic Oncology, Department of Orthopedic Surgery, Ludwig-Maximilians-University Munich, Germany**

Prof. Hans Roland Dürr graduated Medical School at the University of Giessen and Würzburg. From 1991 to 1993 he worked at the Department of General and Abdominal Surgery in Mainz, followed by the Orthopaedic Clinic of the Ludwig-Maximilians-University Munich, where he finished as orthopaedic specialist. From 2001 to 2003 he was senior physician and head of department tumour orthopaedics. Since 2003 Prof. Dr. Dürr is Head Orthopaedic Oncology, Department of Orthopaedic Surgery, Ludwig-Maximilians-University Munich, Germany. He is a member of the German Society of Orthopaedic Surgery (DGOOC), the Working Group tumours DGOOC, the South and North German orthopaedic association, the Societe Internationale de Chirurgie orthopédique et de Traumatology (SICOT) of the European Musculo-Skeletal Oncology Society (EMSOS), the International Society of Limb Salvage (ISOLS) and the Connective Tissue Oncology Society. Furthermore Prof. Dr. Dürr is a regular reviewer of the "Journal of Bone and Joint Surgery", "Clinical Orthopaedics and Related Research.

Dr. Janice Dutcher**Professor of Medicine, New York Medical College, USA**

Dr. Janice Dutcher is a graduate of the University of California Davis medical school and completed residency training in Chicago, at Rush-Presbyterian St Lukes Hospital. She completed her fellowship in oncology at the National Cancer Institute, Baltimore Cancer Research Program. She directed the high dose Interleukin-2 programs at Montefiore Medical Center, Our Lady of Mercy Medical Center, and St Luke's Roosevelt Hospital Center in New York and is a founding member of the Cytokine Working Group. She is Professor of Medicine, New York Medical College. She is the immediate past chair of the Renal Cancer subcommittee in the Eastern Cooperative Oncology Group. She has participated in clinical trials of most of the new agents presently available for the treatment of kidney cancer and melanoma and provides lectures and perspectives on the management of these diseases. She has published more than 200 peer reviewed papers in oncology research, and more than 150 invited papers and chapters.

Dr. Michael A.S. Jewett**Professor of Surgical Oncology, University of Toronto, Canada**

Dr. Michael Jewett is a member of the University of Toronto Faculty of Medicine, where he is Professor of Surgery (Urology), and the Department of Surgical Oncology at the Princess Margaret Cancer Centre of the University Health Network. He is the chair of the Kidney Cancer Research Network of Canada and holds 2 academic Chairs, one from the Canadian Institutes of Health Research, (Farquaharson. Clinical Research Chair in Oncology). He is a member of the new USA NCI Renal Task Force. In 2011, he was awarded the AUA Distinguished Contribution Award, the SUO Medal, the CUA Award and the Postgraduate Teaching Award by UofT Urology for best surgical teacher. He recently received the Queen's Jubilee Medal on the recommendation of the Canadian Medical Association. He has published extensively in UroOncology and is a regular Visiting Professor around the world.

Dr. Georgios Kallinikas**Urology Department "Konstantopouleion" Hospital Nea Ionia, Athens, Greece**

Georgios Kallinikas was born in 1977 in Athens Greece. In 1995 he graduated from the 22nd public high school of Athens. From 1997 to 2001 he studied physical therapy in Lamia (Greece). Immediately after his graduation Dr. Kallinikas begun his studies in the medical school of the National and Kapodistrian University of Athens Greece from which he graduated in 2006. From 2002 to 2003 he paid his duty in the Greek Air Force. From 2007 to 2008 he offered his services as a doctor at the medical unit of the isolated island of Folegandros, Greece and the hospital of the island of Syros, Greece. In 2009 he started his residency in urology which is about to end at the beginning of 2014. Since 2012 Dr. Kallinikas voluntarily assists the VHL family alliance of Greece. In 2013 he got a special training on VHL at the university of Freiburg am Breisgau (Germany). He also has a Msc in the clinicopathological study of human neoplasms and regularly participates in major congresses regarding his specialty and has been the author or co-author of several publications.

Prof. Dr. Börje Ljungberg**Professor of Urology, Department of Surgical and Perioperative Sciences, Urology and Andrology, Umeå University, Sweden**

Börje Ljungberg received his MD in 1975, and his PhD in urology in 1986, both from Umeå University, Umeå, Sweden. He is currently a Professor of Urology and Andrology, at the University Hospital of Umeå, Umeå Sweden. He has previously been president of the Nordic Urological Associations renal cell carcinoma group as well as secretary of the Swedish Urological Association. His main field of interest is urological oncology, especially renal cell and bladder carcinoma. Börje Ljungberg has performed studies on tumour genetics, DNA ploidy, angiogenesis and cell cycle regulation.

Dr. Paul Nathan

Consultant Medical Oncologist, Mount Vernon Cancer Centre, UK

Dr Nathan received his first medical degree from Cambridge University and qualified in medicine at University College London, both achieved after earlier degrees (including a PhD) specialising in immunology. He initially pursued cancer research in academia and in the pharmaceutical industry before finally deciding to pursue a clinical career.

He has a specialist interest in the treatment of renal cell carcinoma (kidney cancer) and melanoma. He is a member of the National Cancer Research Institute groups for both renal carcinoma and melanoma, chairs the rare melanoma subgroup and was secretary of the UK Melanoma Study Group. He also is chairing the panel currently developing the national ocular melanoma guidelines. He is lead investigator on many clinical trials and has an active research program.

His major interests are in the use of targeted therapies to treat advanced renal carcinoma, the development of imaging biomarkers in the management of this disease, and in the development of selective treatments for genetically defined subtypes of melanoma. He has published many papers and contributed to a number of textbooks.

Kathy Oliver

Co-Director, International Brain Tumour Alliance, UK

The International Brain Tumour Alliance (IBTA) is a worldwide cooperative initiative involving brain tumour support, advocacy and information groups. The IBTA advocates for equitable patient access to brain tumour therapies; encourages the establishment of brain tumour support groups in countries where they don't yet exist; and raises awareness of the challenges of this devastating disease. The IBTA's two major annual awareness raising initiatives ("The International Brain Tumour Awareness Week" and "The Walk Around the World for Brain Tumours") have been supported by up to 197 brain tumour and cancer-relevant organisations around the globe. The IBTA also publishes 12,000 copies of a major magazine each year called Brain Tumour which focuses on news of interest to the international brain tumour community. The magazine is distributed for free to recipients in 109 countries. Kathy Oliver's son, Colin, was diagnosed in 2004 at age 24 with a brain tumour. He courageously survived for seven-and-a-half years but passed away, at age 32, in August 2011. Colin's incredible courage, determination and fortitude provided Kathy with the driving force and inspiration for her involvement with the IBTA and the wider cancer community.

She is currently involved in a range of high-level international initiatives and projects in Europe addressing brain tumour, rare cancer and access to therapy issues amongst others. She is the Vice Chair of the European CanCer Organisation (ECCO) Patient Advisory Committee and Co-Chair of the EUPATI Project Advisory Board. As an ex-freelance journalist - she contributes articles to a number of cancer community-relevant publications. She is also the Patient Issues Editor of the European Association of NeuroOncology's (EANO) online free-access journal.

Dr. Shyam Kishore Shrivastava

Professor & Head in Radiation Oncology, Department of Radiation Oncology, Tata Memorial Hospital, Parel, Mumbai, India

Dr. Shyam Kishore Shrivastava was trained at and visited hospitals in UK, USA and Germany. He is teacher for MD radiotherapy, medical physics, oncology nursing and radiotherapy technologists' courses in Mumbai. Shrivastava is examiner for various Universities for MD (radiotherapy) and DMRT, member of Editorial Board for 'Journal of Clinical Radiotherapy & Oncology', member of Review Board for International J. Radiat. Oncol. Biol. Phys., 'Clinical Oncology'.

Furthermore he is member of Several Scientific societies such as ASTRO (American Society for Therapeutic Radiology & Oncology), ESTRO (European Society for Therapeutic Radiology & Oncology), ABS (American Brachytherapy Society), AROI (Association of Radiation Oncologists' of India), AMPI (Association of Medical Physicists' of India) and IAHOM (Indian Association of Hyperthermia in Oncology & Medicine).

Shrivastava is expert and advisor for setting-up and up-grading of cancer institutions in Maharashtra, Gujarat, Bihar, Bangladesh and Yemen. He is involved in several research projects from IAEA, WHO, DST, ICMR and intramural projects and published over 50 scientific papers in international and national journals, as well as chapters in books.

Prof. Charles Swanton

Chair in Personalised Cancer Medicine at the University College London Cancer Institute and Consultant Medical Oncologist at UCL Hospitals, UK

Charles Swanton completed his PhD in 1998 at the Imperial Cancer Research Fund Laboratories on the UCL MBPhD programme before completing his medical oncology and Cancer Research UK funded post-doctoral clinician scientist training in 2008. He was appointed Medical Research Council and Cancer Research UK senior clinical research fellow and Group Leader of the Translational Cancer Therapeutics laboratory at the CR-UK London Research Institute in 2008, focussing on personalised cancer medicine through an understanding of mechanisms of drug resistance, intratumour heterogeneity and genomic instability.

He combines his laboratory research with clinical duties focussed on biological mechanisms of drug resistance in lung and breast cancer. Prof. Swanton worked as a consultant medical oncologist at the Royal Marsden Hospital with an interest in early phase drug development for the treatment of specific subtypes of metastatic solid tumours (2008-2011). He has had lead or corresponding author publications in Nature, Cancer Cell, PNAS, Lancet Oncology and The New England Journal of Medicine. He is a member of several translational research scientific committees including AICR and Cancer Research UK Sciences Committee. Prof. Swanton was made Fellow of the Royal College of Physicians in April 2011 and was appointed to the Chair in Personalised Cancer Medicine at the University College London Cancer Institute and Consultant Medical Oncologist at UCL Hospitals in November 2011.



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.



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).



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.



Gilles Frydmann

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.



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.

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.



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.



Robin Martinez

**Kidney-Onc mailing list
(one of ACOR's many cancer listservs)**

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.



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.



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.



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)



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.

We have attempted to compile this Conference Report with the utmost care. However, errors and omissions cannot be ruled out. IKCC the authors, translators and designer are not liable for any errors. Please notify the authors immediately (info@lebenshauspost.org) if you find any errors.

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