

EXPANDING CIRCLES

in Supporting Kidney Cancer



International
Kidney Cancer
Coalition

4th International Conference for
Organisations Representing Patients
with Kidney Cancer
3 - 5 April 2014, Amsterdam, Netherlands



Conference Report



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Acknowledgement

We would like to thank the following funders who supported the 4th IKCC Conference with an unrestricted educational grant: Bayer, GSK, Novartis and Pfizer.

At the request of the Leadership Team, IKCC received grants from four companies. This funding is not related to any objectives of IKCC or any objectives/content of the 4th IKCC Conference in Amsterdam.

The idea, conception, planning, preparation, realisation, management and the summary of the EXPANDING CIRCLES 2014 Conference was the responsibility of the IKCC Leadership Team 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 organisations 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 organisations. 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 organisations. All such organisations are welcome to participate.

Our Mission:

The global collaboration of national patient groups supporting those affected by kidney cancer:

- To empower one another
- To raise awareness of kidney cancer
- To speak with a common voice in research and treatment and care.

Our Vision:

Empowering organisations to improve the lives of those affected by kidney cancer worldwide.

Our Objectives:

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

Our Core Values:

- 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



**“Kidney Cancer: More Than
One Million People Worldwide
Are Living With This Significant And
Increasing Health Issue.
So Let’s Raise Awareness Together!”**



**Canada
Deb Maskens
Kidney Cancer Canada**

Day 1 – Thursday, 3rd April

It was April 2014, not quite tulip time but the daffodils and blossoming trees were beautiful. From 22 countries spanning 6 continents, we met in Amsterdam for the International Kidney Cancer Coalition's fourth conference for organisations representing patients with kidney cancer to share best practices, to exchange experiences, and to work toward global solutions for kidney cancer patients wherever they live. A wonderful cause led to a wonderful meeting for all.



10:00 – 11:45

Optional pre-meeting, Kidney Cancer 101
Introduction to kidney cancer: What is cancer?
And specifically, how is kidney cancer
different from other cancers?

Speakers: Dr. Axel Bex (NL) and Dr. Danny Heng (CDN)
Moderators: Berit Eberhardt (DE) and Robin Martinez (USA)

In this introduction to renal cell carcinoma (RCC), urologist Axel Bex discussed surgeries including nephrectomy, partial nephrectomy, and laparoscopic or keyhole surgery to the kidney. Any of these can be curative, especially for early-stage kidney cancer. Later stages of RCC often require surgery to remove metastases or repair bone metastases. In addition, there are less invasive surgical alternatives such as cryo-ablation, radiofrequency ablation, and radiosurgery (highly focused radiation). RCC does not respond well to low levels of radiation or to traditional chemotherapy. Oncologist Danny Heng explained current oncological treatments. New types of drugs have been invented to treat RCC including blood-vessel growth inhibitors such as axitinib, bevacizumab, pazopanib, sorafenib, and sunitinib; mTOR inhibitors like everolimus and temsorolimus; and immunotherapy including Interleukin-2 and the new investigational drugs known as anti-PD1 and anti-PDL1. In the future, we hope research will discover how to use molecular biomarkers to predict which drug will work best for which RCC patient.

13:00 – 13:15

Welcome to the
4th IKCC EXPANDING CIRCLES in
Supporting Kidney Cancer

IKCC co-chairs Dr. Rachel Giles (NL) and
Deb Maskens (CDN)

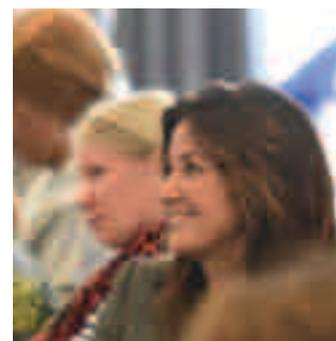
Deb Maskens and Dr. Rachel Giles paired beautifully to give a funny, informative, and warm welcome to all delegates and then moved into our first conference presentation.

**“In So Many Countries Even
The Minimum Acceptable Standards
Of Care For Kidney Cancer Patients
Are Not Available!
We Really Need To Advocate
For Changes!”**

**Ghana
Juliet Ibrahim
Juliet Ibrahim Foundation**



Day 1 – Thursday, 3rd April



13:15 – 15:30

1. The “Burden Of Cancer”: A Social and Economic Challenge

Speaker: Prof. Dr. Peter Boyle (UK/FR)

2. How Personal Engagement Can Make a Huge Difference. An Outstanding Example Of Change: Hospice Africa

Speaker: Prof. Dr. Anne Merriman (UGA)

3. Kidney Cancer Trends & Statistics Around The World

Speaker: Dr. Danny Heng (CDN)

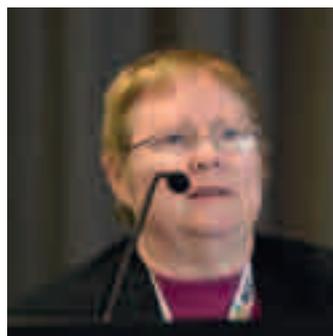
Moderators: Dr. Rachel Giles (NL) and Deb Maskens (CDN)

Dr. Peter Boyle provided an epidemiologist’s perspective on cancer as a global problem, specifically noting the dramatic increase of cancer in low and medium income countries. Huge increases in survival have come from a series of small, incremental steps, not a “magic bullet.” While significant advances have been made against breast, leukemia, stomach, and testes tumours, the mortality rate for kidney cancer has not improved. Incidence of kidney cancer has been steadily rising since 1975. Dr. Boyle expressed concern about great and growing disparities.

Dr. Anne Merriman from Uganda was welcomed and congratulated for her nomination for the Nobel Peace Prize. She is a pioneer in palliative care in developing countries in Africa. Despite her years of campaigning to make affordable oral morphine widely available for cancer pain relief, it is currently available in only 15 of the 56 African countries. Less than 5% of cancer patients in Africa have access to chemotherapy or radiation. Radical solutions are required – the status quo is simply not an appropriate response. www.hospiceafrica.or.ug

Canadian medical oncologist Dr. Danny Heng noted 208,000 cases of kidney cancer are diagnosed each year. Reported incidence is higher in North America, Australia, and New Zealand. The International Metastatic Renal Cell Carcinoma Database Consortium (IMDC) tracks over 3700 patients from 26 institutions around the world. This wealth of information identifies trends in the use of therapies, answers important clinical questions, and generates hypotheses ahead of clinical trials. Dr. Heng noted we can apply “prognostic” scoring methods developed by the IMDC but “prediction” is still not possible: “Medians are just medians. Half live longer, half live shorter. Many live much longer.”

Day 1 – Thursday, 3rd April



16:00 – 17:30

Prevention, Diagnosis, Risk Assessments, Markers and Early Treatments of Kidney Cancer. What can patient organisations recommend?

Speakers: Prof. Dr. Kerstin Junker (DE) and James Brandon (UK)
Moderator: Joyce Graff (USA)

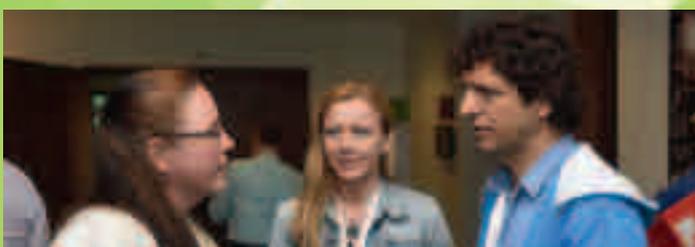
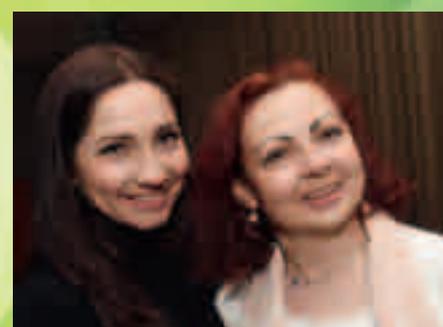
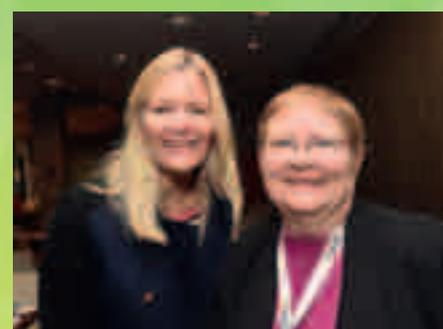
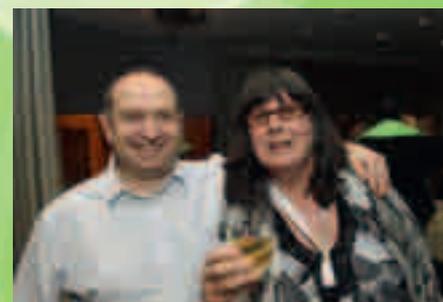
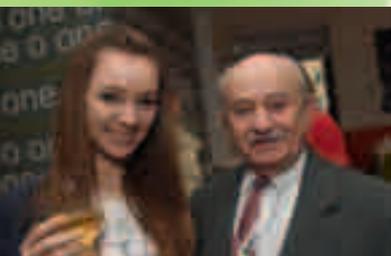
Kidney cancer is treated most successfully when it is found at an early stage. We are working on this from two directions:

- (1) research to find biomarkers and
- (2) raising awareness of early indicators so people will visit a doctor when needed.

Dr. Junker described the search for biomarkers, substances in blood or urine that might indicate the presence of disease. While there are some candidate biomarkers, we do not yet understand exactly what they are telling us and how best to use them. Once tumour tissue is available (through biopsy or surgery), careful analysis of the DNA of the tumour itself will indicate the cell type and the number of genetic alterations that have already occurred within the tumour. We need better ways to predict which of the available drugs will be most helpful in this case.

James Brandon explained the research behind the UK's "Blood in Pee" campaign, raising awareness of the importance of reporting to the doctor any blood seen in the urine, even if a small amount only one time. This helps identify early stage kidney or bladder cancer. The organisation field tested the language and the best ways to approach their target markets, with distinctly different approaches to men than to women. Transferring these ideas to another country would require similar research into the most culturally appropriate ways to approach these topics with consumers.

Day 1 – Impressions of the Welcome Dinner



**“It Is Extremely Valuable That Research
Is Generating More Effective
Treatments In Kidney Cancer.
But What Does This Really Mean
If Patients Don’t Have Access To
Affordable Drugs?”**



**Brazil
Luciana Holtz
Instituto Oncoguia**

Day 2 – Friday, 4th April



07:30 – 08:30

Early breakfast session (optional) Psychological and Social Support

Speaker: Dr. Eveline Bleiker (NL)
Moderator: Robin Martinez (USA)

Dr. Eveline Bleiker talked about how people involved in cancer treatment – patients, family members, and professionals alike – have gradually learned to value quality of life as an important factor in treatment. This was not even a topic of discussion until man went to the moon! Today we regard the psychological wellbeing of patients and their family members as a vital part of success, and we work to build social support structures to care for them. Questions and comments showed keen interest in such services and the need for them. Every onlooker empathised with one caregiver's expression of pain and the healing that came when a therapist inspired a moment of fresh communication between the patient and caregiver. The often long and draining ordeal of treatment must be countered with support for the emotional well-being of patient and family. We still have far to go.

09:00 – 10:30

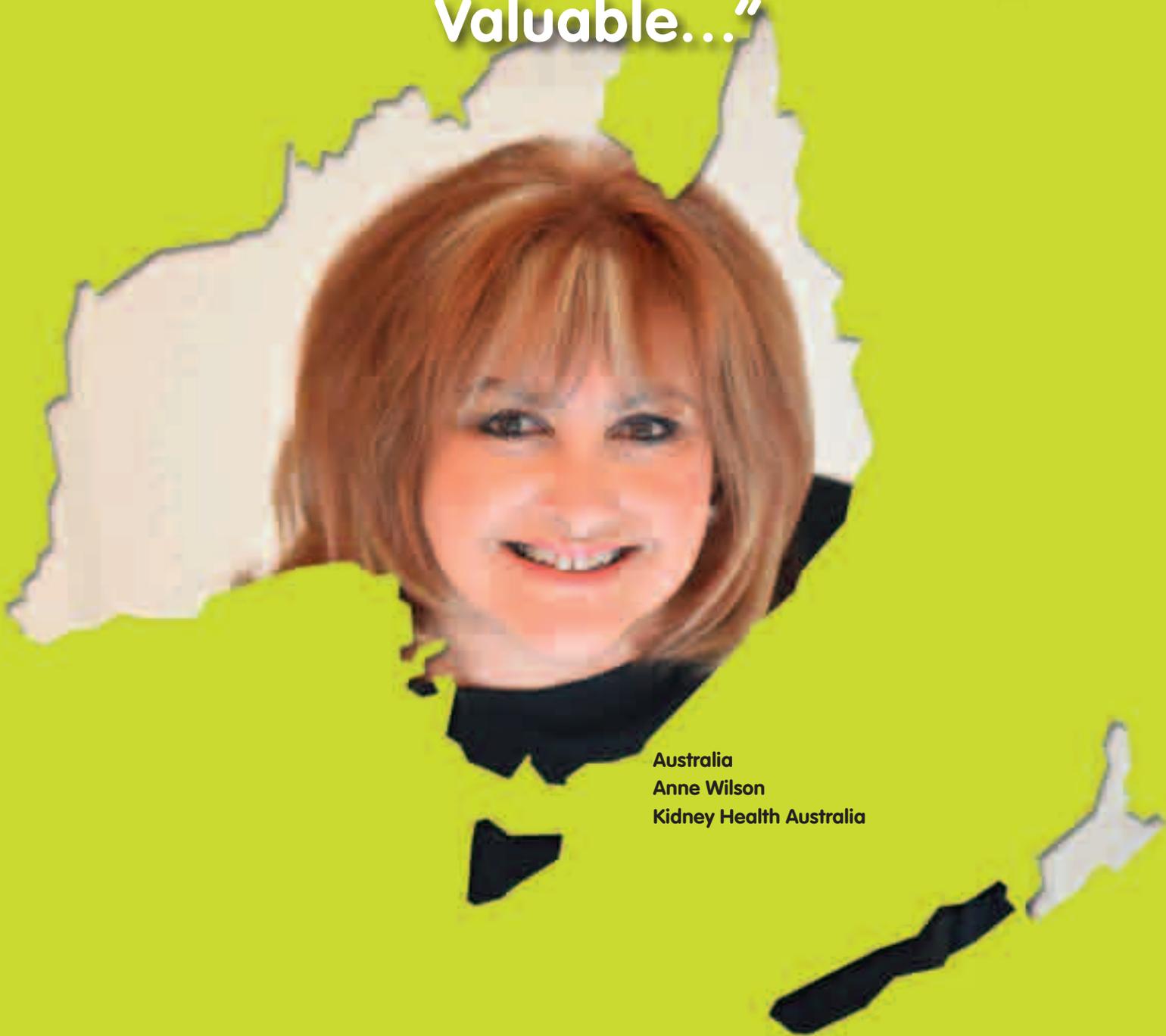
Kidney Cancer Treatment Update • Current Urological and Oncological Treatments • Clinical Trials & Future Directions

Speakers: Dr. Axel Bex (NL) and Dr. Danny Heng (CDN)
Moderator: Berit Eberhardt (DE)

In his talk urologist Axel Bex first showed the changes in stages and surgical management of renal tumours. Treatment of so-called small renal masses is more challenging than ever: partial nephrectomy, ablation, Cyberknife, or even active surveillance are widely discussed among experts. He also discussed neoadjuvant treatment of locally advanced disease (shrinking tumours with drugs before surgery) and the role of surgery of the primary tumour in the era of the targeted therapies.

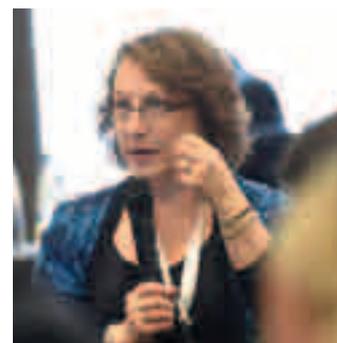
Oncologist Danny Heng stated we've come very far with the new drugs for renal cell carcinoma, but in the future, biomarkers will hopefully predict the efficacy of such treatment. He presented the mechanisms of currently investigative treatments like AGS-003 vaccine, PD1 and PDL1 inhibitors, and cabozantinib. He concluded that medical advances cannot be possible without the participation of thousands of clinical trial participants worldwide and emphasised the importance of clinical research.

**“Kidney Cancer Patient Groups
Around The World Don’t Have To
Reinvent The Wheel.
Sharing Our Information, Materials
and Best Practices Is Extremely
Valuable...”**



**Australia
Anne Wilson
Kidney Health Australia**

Day 2 – Friday, 4th April



11:00 – 12:30

Strengthening Your Organisation: Fundraising & Sustainability -

Speaker: Anne Wilson (AU)

Volunteer Management -

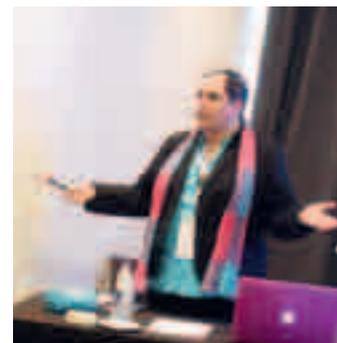
Speaker: Prof. Michael Herbst (ZA)

**Moderators: Anne Wilson (AU) and
Prof. Michael Herbst (ZA)**

Anne Wilson from Australia spoke on fundraising and sustainability, highlighting the challenges encountered by organisations regardless of their size or geography. A range of traditional fundraising concepts were discussed including donations, appeals, bequests, and philanthropy as well as more commercial concepts such as partnerships and cause-related marketing. The key message on sustainability focused on the importance of securing multiple sources of income rather than becoming dependent on one main source.

The presentation by Michael Herbst of South Africa covered all aspects of volunteer management. Michael highlighted the need for organisations utilising volunteers to develop a comprehensive volunteer policy addressing appointment; a description of the types of tasks volunteers are expected to undertake; the need for a developed induction and training program for new volunteers; indemnity insurance; and an appraisal system. In addition, groups must have a process in place for termination of volunteers should that be necessary.

Day 2 – Friday, 4th April



14:00 – 15:30

The marketplace session: Capacity building and organisational issues for patient groups

- Peer/Patient Support

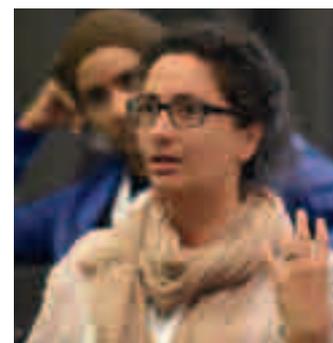
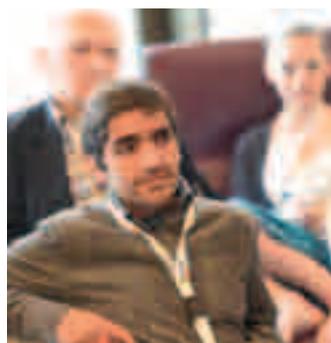
Catherine Madden (CDN) and Rose Woodward (UK)

The goal was to share different methods of support that patient groups can offer to patients and carers and discuss some of the advantages and disadvantages of those methods. Methods included one-on-one calls/meetings, online discussion forums, social networks like Facebook, patient blogs, etc. Group discussion focused on supporting and empowering both the patient/carer and the volunteer providing the support. Participants received a handout covering a variety of topics including who should provide support, resources available to patients, the support conversation itself and how to look after the person providing this often emotionally draining support. One organisational model for a triage system was also discussed, reviewing the intake call, the task of matching the caller to an appropriate support person, follow-up, and confidentiality issues. Peer/patient support is truly one of the most important roles patient groups provide. Preparation and guidelines ensure it is a positive experience for both the patient and the volunteer.

- Side Effect Management

Berit Eberhardt (DE)

In this marketplace session, Berit Eberhardt reminded the participants that quality of life is the most important issue for those chronically treated with cancer drugs; and side effect management is crucial for quality of life. Patient organisations can become a fundamental source for tips and recommendations about side effects. For example, the German organisation collects all the tips and recommendations they can get, offering these to everybody via leaflets, talks at gatherings, telephone support, online platforms, blogs, and Facebook groups. In this process, connections with patients are most valuable: e.g. patients on treatment for a long time can connect to patients starting with the treatment; to doctors, nurses and their associations; and to other cancer associations and organisations, especially those whose patients use similar therapies. Make sure all your tips and recommendation are reviewed by your medical advisory board.



• How to Generate 'Patient Stories'

Robin Martinez (USA)

Robin Martinez led group discussions on generating patient and caregiver stories, valuable to your group at any point in the person's disease journey. Sharing experience builds a sense of community and provides a roadmap for others. It brings awareness of kidney cancer and of your group to the outside world, gaining support for research and legislation, teaching about symptoms and treatment, empowering patients and carers to advocate for themselves, modeling shared decision-making, and improving medical care. Stories explain where to get help and make isolated patients feel connected and encouraged. Stories let your donors know they have made a difference. A good story comes from your relationship with a person. Collect stories at meetings, in waiting rooms, online, through a questionnaire in your newsletter, or just chatting. Remember to protect the storyteller's identity so they're not subjected to junk mail, marketing calls, or unwanted publicity. Stories are a powerful tool. Use them.

• Patient Information/Support in Developing Countries

Prof. Michael Herbst (ZA) and Vandana Gupta (IND)

Patient groups raise hope, increase awareness and support, and provide health information to everyone affected by cancer to improve their quality of life.

In many developing countries the sharing of information is problematic due to multiple languages and dialects. There is little written material, a problem made worse by low literacy levels, and there is little access to the internet. Talks, simple films, the presence of cancer survivors, and celebrity endorsements help to spread knowledge.

Medical doctors are treated as gods. Patients who question may find their treatment suffers. Overloaded doctors do not find the time to provide needed information to patients. Here again, language barriers bedevil communication.

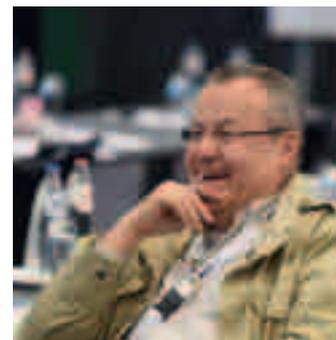
Most people travel long distance to get specialised treatment. Support is needed in terms of a place to stay. Availability of blood is a major problem, and donation of any other human tissue is practically non-existent. People often don't know about the few available government programs.

**“The Global Voice Of
Kidney Cancer Patients Must Be
Heard Loud And Clear. We Need To
Strengthen This Voice By Supporting
Patient Groups And Encouraging The
Creation Of New Ones.”**



**India
Vandana Gupta
V Care Foundation**

Day 2 – Friday, 4th April



16.00 - 17.30

IKCC ADVOCACY – Breakout Session / Working Groups Discussing And Collecting Needs/Challenges/ Performances of The Global Kidney Cancer Patient Community

Discussions/Exchange/Brainstorming (45 minutes)
Feedback from individual groups and general discussion (30 minutes)

Moderator: Markus Wartenberg (DE)

Results of Group 1: The Dutch Windmill Group

Topic: Challenges

What are the needs, problems and challenges kidney cancer patient groups are currently facing?

The group identified the following issues:

- Raising sufficient funds
- Competing effectively for funding
- Identifying other resources
- Balancing activities
- Finding good speakers
- Focusing on services
- Providing patient support
- Supporting staff and volunteers to prevent burnout
- Taking care not to grow too fast
- Planning for the succession of staff or volunteers in key job areas
- Getting men to join support groups
- Keeping up with technology
- Referring people to other existing resources rather than duplicating those services
- Learning about the applicable regulations and funding issues for treatment

Day 2 – Friday, 4th April



16.00 - 17.30

IKCC ADVOCACY – Breakout Session / Working Groups Discussing And Collecting Needs/Challenges/ Performances of The Global Kidney Cancer Patient Community

Discussions/Exchange/Brainstorming (45 minutes)
Feedback from individual groups and general discussion (30 minutes)

Moderator: Markus Wartenberg (DE)

Results of Group 2: The Dutch Tulip Group

Topic: Leadership

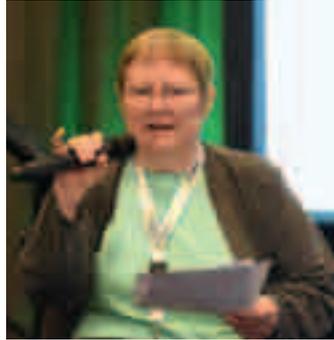
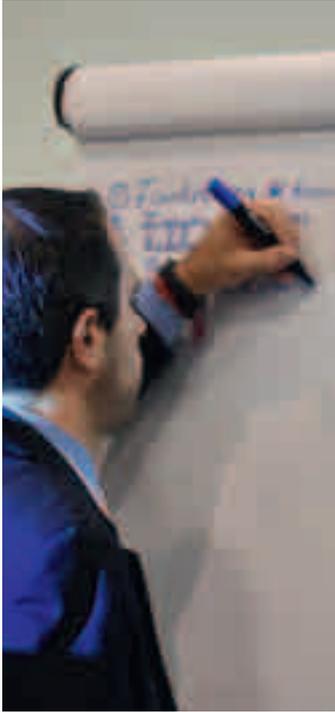
What skills, information, or training do kidney cancer patient group leaders need to strengthen their groups?

It would be valuable to have all of the assets noted; but the most important skill is fundraising knowledge because there is little an organisation can do without money.

Needed:

- Interpersonal skills like networking and relationship building (e.g. to clinicians, media, other organisations).
- Personal skills like open minded and outgoing personality, natural leader, decision making, and willingness to learn.
- Information/knowledge about kidney cancer, available treatment options, guidelines in their country, the local health system, main stakeholders, available social services, understanding of the main gaps and how to bridge those gaps.
- Training in management of time, priorities, media, finances, staff and volunteers, projects, marketing, branding; later, monitoring and evaluation processes, performance development, sustainability, and HTA.

Markus Wartenberg emphasised these skills are not specific to kidney cancer patient advocates. The IKCC supports an initiative for a course called “How to start and run a patient group” to support new leaders. The first course is expected at the end of this year.



16.00 - 17.30

IKCC ADVOCACY – Breakout Session / Working Groups Discussing And Collecting Needs/Challenges/ Performances of The Global Kidney Cancer Patient Community

Discussions/Exchange/Brainstorming (45 minutes)
Feedback from individual groups and general discussion (30 minutes)

Moderator: Markus Wartenberg (DE)

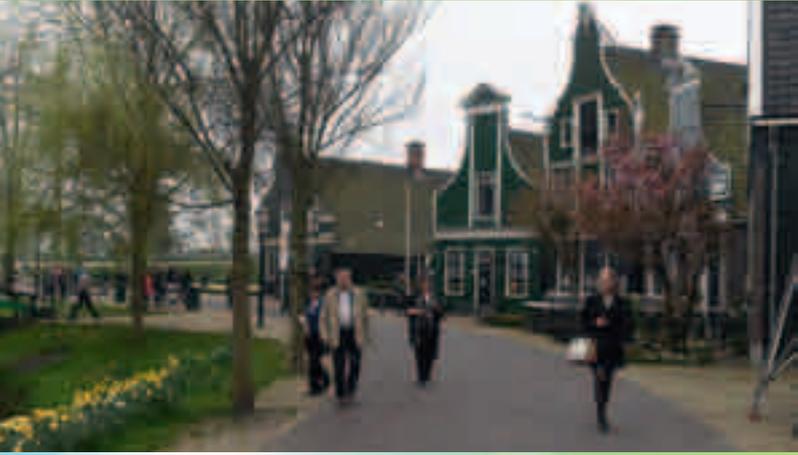
Results of Group 3: The Dutch Cheese Group

Topic: Collaboration

How could the global kidney cancer community (through IKCC) support your efforts in your country?

- Lots of different guidelines and information
- Important to pull this together on one website so we can share
- Library of different materials in one place
- Needs translation and categorisation
- Available for members area only
- Finding an International Ambassador
- Someone to stand up for the whole international community
- International charter for the minimum standards for treatment
- Quality of care from the patients' perspective
- Cancer numbers in some countries are seriously misreported
- Pharmaceutical companies can be useful as they have the local connection
- Ascertain the main players in each region

Day 2 – Impressions of the External Dinner



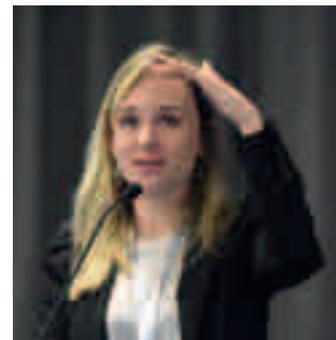
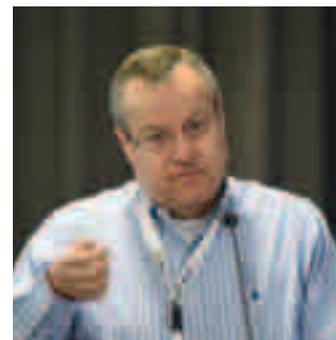
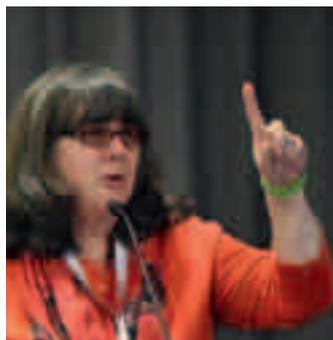
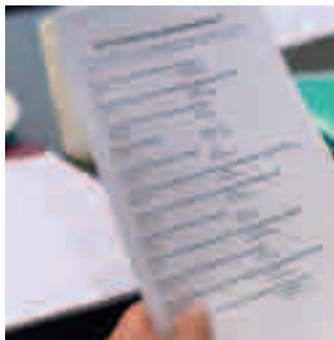


**“Patient Groups Can Help To Improve
the Relevance And Quality Of Research!
That’s Why We Need Patient
Involvement In Kidney Cancer Research
As Early As Possible!”**



**Netherlands
Dr. Rachel Giles
Dutch Kidney + Bladder Cancer Grp.
(Waterloop) & Dutch VHL Org.**

Day 3 – Saturday, 5th April



07:30 – 08:30

Early Breakfast Session (optional) Caregiver Support “Who Cares For The Carer?”

Speaker: Prof. Michael Herbst (ZA)
Moderators: Prof. Michael Herbst (ZA) and Berit Eberhardt (DE)

In this early morning breakfast session Prof Michael Herbst emphasised that a caregiver is anyone who cares for a parent, a sibling, another family member, a friend, or anyone else. He stressed that caregiving could result in caregiver burnout. Caregiver burnout is particularly relevant in oncology where caregivers work with individuals who have life-threatening illnesses and therapy that often has only a limited impact. Michael then provided causes and signs of caregiver burnout, which was followed by an interesting test which every participant was requested to complete: Are you heading for caregiver burnout?

09:00 – 10:30

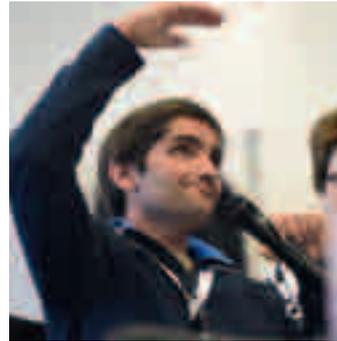
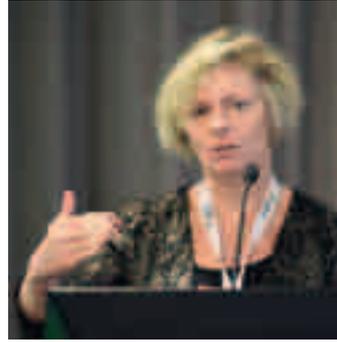
Sharing Best Practices In Kidney Cancer Support & Advocacy

- ARTuR, France
- Instituto Oncoguia, Brazil
- Das Lebenshaus e.V., Germany
- Myrovlytis Trust, UK
- Kidney Cancer Canada, Canada

Moderator: Rose Woodward (UK)

The “sharing best practices” session is always very popular. Our presenters explain their successful special projects with contagious enthusiasm and energy. Their ideas encourage us to try out new and innovative ways of working. Denis Brezillon from France told us about kidney cancer patient days completely organised by volunteers for over 200 attendees. Luciana Holtz told us about using powerful social networking websites to spread hope by telling the truth about cancer statistics in Brazil. Germany’s Berit Eberhardt encouraged us to beg, borrow, or steal ideas from other people to strengthen our own organisations. Then Lizzie Perdeaux from the UK grabbed our attention with SMOG analytics, a process to ensure patient information is clear and understandable. From Canada, Deb Maskens showed us a remarkable video which brings together cancer charities in a campaign for equity of treatment for all Canadian cancer patients.

Day 3 – Saturday, 5th April



11:00 – 12:30

Spotlights On Specific Topics In Kidney Cancer: Renal Tumours in Children

Speaker: Dr. Marry van den Heuvel-Eibrink (NL)

Hereditary Kidney Cancer

Speaker: Eric Jonasch MD (USA)

Moderator: Dr. Rachel Giles (NL)

This session was inspired by topic suggestions in evaluation forms from past IKCC meetings.

Pediatric oncologist Dr. Marry van den Heuvel-Eibrink reviewed kidney tumour types in children. Approximately 90% of all pediatric renal tumours are Wilm's tumours, with a characteristic embryonic cellular origin and a clear and relatively effective treatment guideline. Of the remaining tumours, approximately 70% have an Xp11.2 translocation; these rare RCCs are also seen in young adults. Clear cell sarcomas in the kidney also present unique treatment challenges.

Medical oncologist Dr. Eric Jonasch discussed rare renal tumour syndromes that collectively account for about 10% of all cases of renal cell carcinomas. The most common form of hereditary/genetic/familial RCC is von Hippel-Lindau (VHL) disease, characterised by clear cell RCC as well as tumours in other organs. Other genes mutated in families with RCC seem to point to mitochondrial dysfunction as the source for tumour initiation. These syndromes caused by a single germline gene mutation can provide tremendous insight into RCC cases resulting from accumulated mutations over the course of a lifetime.

13:15 – 14:15

Interactive Session - Delegate Feedback / Outlook

Moderator: Joyce Graff (USA)

At the beginning of the conference we asked each delegate to keep one of three questions in mind throughout the meeting and to report to the group on Saturday. The goal was to get people to focus on ideas they could take home to implement.

1. What three new project ideas will you take home to your organisation for possible implementation in your country?
2. What three questions or recommendations will you take back to the doctors/healthcare system in your country?
3. What three things will you change about how you involve patients and carers in the running of your organisation?

It was good to hear the reports from the delegates. All were impressed with the videos. Ideas for psycho-social support for patients and families, caregiver support, and prevention were frequently mentioned. Many organisations committed to work toward national guidelines for conservative treatment of small renal masses, and to involve patients and families in research and in establishing guidelines as well as in patient support.



14:15 – 14:30

**End Of Conference,
Summary, Feedback-Forms, Closing Remarks,**

Thanks To The Presenters & Sponsors

**Speakers: Anne Wilson (AU) and
Prof. Michael Herbst (ZA)**

What a wonderful gathering of enthusiastic individuals all working towards the same goal – all in the interest of kidney cancer patients. Together we were updated about the latest developments in the diagnosis and treatment of kidney cancer. Some of the leaders in the kidney cancer world shared their knowledge, skills and experiences with us in such a professional yet down-to-earth manner. It may sound like a cliché: this was the best Expanding Circles Conference so far!

Highlights included meeting new friends and colleagues, networking, getting ideas, and learning from each other. It felt like the 3-day conference lasted only a single day. It was with a lot of gratitude, coupled with sadness, that we parted from each other – each one going back to implement what we learned in Amsterdam. It is with great expectation that we look forward to the 5th Expanding Circles conference wherever it may be hosted.

Amsterdam 2014: Feedback

Some comments from Emails and the Evaluation Forms...

There was a lot of important information that we can learn from.

THANK you very much for this important & effective meeting of experts and representatives of patients.

My first attendance to IKCC meeting. I attended a lot of international meetings in my professional career. The IKCC meeting is likely the best I have ever attended.

IKCC 2014 offered us a great deal of ideas, experience sharing and valuable informations which presents a base for our association to rely as it is on its first days.
THANK YOU!

Fantastic meeting! THANK you so much for allowing me to be part of such an exciting movement.

IKCC is really one of the few places where I can get pretty good ideas for my association.

THANK you for an exceptional opportunity to learn from an extraordinary group of experts from around the globe. I especially loved learning about the different problems faced by people from all different countries and the need for cultural sensitivity while helping one another.

Thank you so much for a wonderful conference! I came away inspired by all the wonderful resources the IKCC has brought together from around the globe! How refreshing it was to hear the many different perspectives and challenges people face in different

places around the world. I was truly enriched by attending the conferences, and I am grateful to you for making me feel so welcome to the group as a last minute addition!

Let me sincerely thank IKCC for the possibility to take part in the Kidney Cancer Conference. It was really an important experience for me, as well as for kidney cancer patients in my country. Great speakers and interesting motivating stories!

I have to thank you for the excellent organisation of this 4th IKCC Conference. Everything was more than perfect: the subjects discussed, the speakers, the hotel. Last year I was very touched by the patients testimonial. This year, I've been amazed by the strong organisations that advocate kidney cancer disease.

The meeting this year is better than the earlier ones in terms of content and sharing. I like to be a part of this venture as it creates a difference in thoughts and action.

I have to thank you for everything, it was a unique chance for me and for my country also, exchanging information about cancer it's a wonderful experience.

Participants

Australia	Kirren Grennan	Kidney Health Australia
Australia	Anne Wilson	Kidney Health Australia
Brazil	Luciana Holtz	Instituto Oncoguia
Canada	Catherine Madden	Kidney Cancer Canada
Canada	Deborah Maskens	Kidney Cancer Canada
China	Zhenxi Zhong	Shanghai Roots & Shoots
Finland	Timo Koponen	The Association for the Finnish Cancer Patients
France	Denis Brezillon	A.R.T.u.R (Association pour la Recherche sur le Tumeurs du Rein)
Germany	Dr. Kinga Mathe	Das Lebenshaus e.V
Germany	Berit Eberhardt	Das Lebenshaus e.V.
Ghana	Sonia Ibrahim	Juliet Ibrahim Foundation
Ghana	Juliet Ibrahim	Juliet Ibrahim Foundation
Greece	Athina Alexandridou	VHL Family Alliance Affiliate in Greece
Hungary	Jolan Demeter MD	Hungarian League Against Cancer
India	Jyoti Patil	V Care Foundation
India	Vandana Gupta	V Care Foundation
Kosovo	Naim Berisha	Kosovo Association for Cancer Care (KACC)
Kosovo	Dr. Luan Percuku	Kosovo Association for Cancer Care (KACC)
Netherlands	Henny Berisha	VHL Netherlands
Netherlands	Barbara Bezemer	Belangenvereniging Von Hippel Lindau
Netherlands	Saskia Gooskens	Erasmus MC - Sophia Children's Hospital
Netherlands	Dr. Rachel Giles	Dutch Kidney + Bladder Cancer Grp. (Waterloop) & Dutch VHL Org.
Poland	Izabella Latwinska	Association "GLADIATOR"
Poland	Tadeusz Rudzinski	Association "GLADIATOR"
Poland	Tadeusz Wlodarczyk	Association "GLADIATOR"
Portugal	Paulo Zoio	Portuguese Kidney Patients Association (APIR)
South Africa	Prof. Michael C. Herbst	Cancer Association of South Africa (CANSA)
UK	Elizabeth Perdeaux	Myrovlytis Trust
UK	Rose Woodward	Kidney Cancer Support Network
UK	Andy Thomas	Kidney Cancer Resource
Ukraine	Inna Krulko	Ukrainian Union of Patients' Organisations (UUPO)
USA	Alison Hahn	Kure It Cancer Research
USA	Ilene Sussman	VHL Alliance
USA	Joyce Graff	Powerful Patient Inc.
USA	Robin Martinez	Smart Patients, Inc.
IKCC-Support	Markus Wartenberg	IKCC / Das Wissenshaus GmbH
IKCC-Support	Julia Black	IKCC / Das Wissenshaus GmbH

*LT - Leadership Team
AC - Advisory Council
Partic. - Participant*

www.kidney.org.au	kirren.grennan@kidney.org.au	Partic.
www.kidney.org.au	anne.wilson@kidney.org.au	LT
www.oncoguia.org.br	presidencia@oncoguia.org.br	Partic.
www.kidneycancercanada.ca	cmadden@kidneycancercanada.ca	Partic.
www.kidneycancercanada.ca	dmaskens@rogers.com	LT
www.jgi-shanghai.org	zhenxi.zhong@jgi-shanghai.org	Partic.
www.cancer.fi	timohkoponen@welho.com	AC
www.artur-rein.org	asso-artur@artur-rein.org	Partic.
www.lh-nierenkrebs.org	nierenkrebs.stuttgart@lebenshausgruppen.org	Partic.
www.lh-nierenkrebs.org	berit.eberhardt@daslebenshaus.org	LT
www.julietibrahimfoundation.org	Info@julietibrahimfoundation.org	Partic.
www.julietibrahimfoundation.org	Info@julietibrahimfoundation.org	Partic.
www.vhlgr.blogspot.gr	hellas@vhl.org	Partic.
www.rakliga.hu	jolan.demeter@gmail.com	Partic.
www.vcarecancer.org	vcare24@gmail.com	Partic.
www.vcarecancer.org	vcare24@gmail.com	AC
	kacc.n.berisha@gmail.com	Partic.
	luan.percuku@gmail.com	Partic.
www.vonhippellindau.nl	vhl.info.nl@gmail.com	Partic.
www.vhl.nfk.nl	barbara@vonhippellindau.nl	Partic.
	s.gooskens@erasmusmc.nl	Partic.
www.waterloop.nfk.nl AND www.vhl.nfk.nl	r.giles@umcutrecht.nl	LT
www.gladiator-prostata.pl	stowarzyszenie.gladiator@poczta.fm	Partic.
www.gladiator-prostata.pl	stowarzyszenie.gladiator@poczta.fm	Partic.
www.gladiator-prostata.pl	stowarzyszenie.gladiator@poczta.fm	Partic.
www.apir.org.pt	apir@apir.org.pt	Partic.
www.cansa.org.za	mherbst@cansa.org.za	LT
www.BHDSyndrome.org	lizzie@myrovlytistrust.org	Partic.
www.kidneycancersupportnetwork.co.uk	kcsn@btinternet.com	LT
www.ikcc.org	andy.thomas@fit-vibes.co.uk	AC
www.patient.in.ua	krulkoin@gmail.com	Partic.
www.kureit.org	alisonh@kureit.org	Partic.
www.vhl.org	director@vhl.org	Partic.
www.powerfulpatient.org	joyceg98@gmail.com	LT
www.smartpatients.com	robin@smartpatients.com	AC
www.ikcc.org AND www.daslebenshaus.org	markus.wartenberg@daswissenshaus.de	IKCC
www.ikcc.org	julia@juliablack.co.uk	IKCC

Amsterdam Patient Charter for Global Kidney Cancer Care

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

The Charter is based on a survey extended to 34 patient group leaders with a special interest in kidney cancer, located in 20 countries spread over 6 continents. Based on the 22 responses, this charter represents the global response that all kidney cancer patients should be entitled to, in order of reported importance (Table 1):

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

The Charter was developed in Amsterdam in April 2014, when the IKCC convened a meeting of leading kidney cancer experts and advocates from diverse geographic regions. This group discussed the issues surrounding kidney cancer and outlined the universal standards of care that patients should expect, with the goal of enabling patients to become active, informed and empowered participants at every stage of their treatment. All parties noted that the current situation could be improved if those involved in the care and treatment of patients adopted the principles outlined in the Charter on a global scale.

Signed by:

Australia - Kidney Health Australia, **Anne Wilson**

Brazil - Instituto Oncoguia, **Luciana Holtz**

Canada - Kidney Cancer Canada, **Deb Maskens**

Finland - The Association of Finnish Cancer Patients, **Timo Koponen**

France - ARTuR (Association pour la Recherche sur les Tumeurs du Rein), **Denis Brezillon**

Germany - Das Lebenshaus e.V., **Berit Eberhardt**

Germany - Das Lebenshaus e.V., **Dr. Kinga Mathe**

Greece - VHLFA Alliance Affiliate In Greece, **Athina Alexandridou**

Hungary - Hungarian League Against Cancer, **Jolan Demeter MD**

India - V Care Foundation, **Vandana Gupta**

Kosovo - Kosovo Association for Cancer Care, **Dr. Luan Percuku**

Netherlands - Dutch Kidney Cancer Association, **Lisa Bracht**

Netherlands - Dutch VHL Organisation, **Dr. Rachel H. Giles**

Netherlands - VHL, **Barbara Bezemer**

Poland - Association 'Gladiator', **Tadeusz Wlodarczyk**

South Africa - Cancer Association of South Africa (CANSA), **Prof. Michael Herbst**

Ukraine - Ukrainian Union of Patients Organisations, **Inna Krulko**

United Kingdom - Kidney Cancer Support Network, **Rose Woodward**

USA - Kure It, **Barry L Hoeven**

USA - Powerful Patient, **Joyce Graff**

IKCC Leadership Team Members



RACHEL GILES, M.D.

Von Hippel-Lindau Organisation (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 tumour 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 Organisation since 2009, and an international contact point for Waterloop since 2010. Rachel is currently Co-Chair of the International Kidney Cancer Coalition.

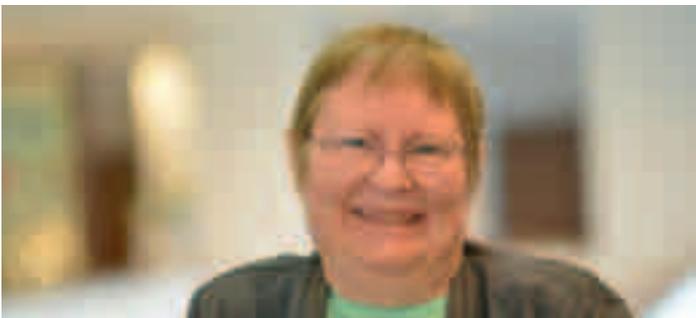


BERIT EBERHARDT

Das Lebenshaus e.V., Germany

Berit was caregiver to her significant other who died at age 39 just one year after diagnosis with kidney cancer. She learned about the disease and its treatment and the needs of patients and caregivers in the same situation. Afterwards she shared her knowledge by establishing a patient support group in her hometown. Shortly after, she became manager of kidney cancer of Das Lebenshaus e.V.

Berit is a compassionate and passionate advocate. Her interest in kidney cancer propels her to raise awareness, connecting people with existing resources and highlighting gaps in services. She works persistently to establish new ideas, materials, and support for those affected by kidney cancer. She provided the patient perspective for the German RCC Guidelines, speaks on kidney cancer topics at German and EU meetings, and is IKCC co-lead for medical treatment and care.



JOYCE GRAFF, M.A.

Powerful Patient Inc., USA

Joyce Graff founded in 1993 the VHL Family Alliance, a national non-profit organisation focused on von Hippel-Lindau (VHL). Over the next 20 years she oversaw its growth into an international network of patient support groups for VHL and other hereditary kidney cancer syndromes. A cancer survivor herself (breast cancer, 1979), she has been the primary researcher and advocate for her husband and son with VHL. She has written extensively on VHL, HLRCC, and pheochromocytoma.

She is a member of the Leadership Team of the International Kidney Cancer Coalition (IKCC) based in Frankfurt, Germany. She served 10 years on the board of the National Organisation for Rare Disorders (NORD) and four years on the Director's Consumer Liaison Group (DCLG) of the US National Cancer Institute. She has been a reporter for the Kidney Cancer Association International Symposia in Chicago (2011 and 2012).

A frequent speaker at national and international cancer meetings, Joyce continues her patient advocacy work through the Powerful Patient and its weekly internet radio show.



MICHAEL C. HERBST, PH.D.

Cancer Association of South Africa (CANSA)

Author and co-author of a large number of scientific papers and various books, Michael has written numerous scientific papers, both nationally and internationally. He was editor of Curationis, the Africa Journal of Nursing and Midwifery, and Nursing Update, a professional journal.

Michael was a member of staff of the Potchefstroom University for Christian Higher Education and University of South Africa. At the University of Venda, he was the first

Professor and Head of the Department of Nursing Science and Acting Dean of the Faculty of Science. His advanced degrees include D Litt et Phil, D. N. Ed., and Dip. Occ. Health. Michael is currently Head of Health at the Cancer Association of South Africa.



DEBORAH MASKENS, M.A.

Kidney Cancer Canada

As co-founder of Kidney Cancer Canada (KCC), Deb has worked tirelessly to ensure equal access to high quality care for kidney cancer patients across Canada. A long-time kidney cancer patient herself, she is a frequent speaker at national and international cancer meetings where she provides the patient voice perspective along with sound advocacy knowledge and experience.

Deb previously served on the board of the Canadian Cancer Advocacy Coalition (CACC) and chaired the Drug Access Working Group, Canadian Cancer Action Network. Currently the Director of Medical Relations for Kidney Cancer Canada, Deb also represents the organisation with the Best Medicines Coalition (BMC) and with the Canadian Organisation for Rare Disorders (CORD). Most recently she led a coalition campaign of 34 cancer organisations (CanCertainty) for full public coverage of oral cancer medications. Deb is a founding member and Co-Chair of the International Kidney Cancer Coalition (IKCC) based in Frankfurt, Germany.



ROSE WOODWARD

Kidney Cancer Support Network (UK)

I was diagnosed with kidney cancer in 2002 and underwent a radical nephrectomy and five years' follow-up in the UK. I now enjoy a full life as a passionate patient advocate dedicated to providing practical and personal support to kidney cancer patients, carers and family members in the UK. I believe patients should be involved in all aspects of their care; from clinical trial design through to shared decision making and beyond into survivorship. I founded the KCSN in 2006 and it is now the largest, most active support network for people touched by Kidney Cancer in the UK. I am proud to be a founding member of IKCC working to help improve the lives of kidney cancer patients wherever they live.



ANNE WILSON

Kidney Health Australia

I am CEO and Managing Director of Kidney Health Australia - the national peak body committed to saving and improving the lives of Australians affected by kidney disease. Over the past 4 years, Kidney Health Australia has taken on advocacy and support for Australians and their families affected by kidney cancer, developing specific resources, a blog, website and telephone information service as well as promoting information about access to clinical trials.

I know several people who have kidney cancer and whilst I have no other personal experience of the disease I am passionate about the need for those with kidney cancer and their families to have equity of access to the latest and most up-to-date information about all aspects of this disease.



Management Services for the IKCC Leadership Team:

Advisor: Markus Wartenberg, Germany

Administrative Coordinator: Julia Black, UK

Das Wissenshaus GmbH, Germany

Schilfweg 2B

61200 Wölfersheim / Germany

info@daswissenshaus.de

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in Supporting Kidney Cancer

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