End of Conference

SUMMARY

Prof Michael C Herbst

Morristown, New Jersey
United States of America
18th April 2015
New Jersey is one of the smallest states in the Union. It is said to be the most densely populated state in the Union. There is an average of 1,189 people per square mile (459 per square kilometre). No other state in the US can boast a higher population density! New Jersey is the only state to have every single county considered "urban" by the Census Bureau.
A Brief History of New Jersey

(1524) Giovanni de Verrazano (an Italian in the Service of King Francis I of France) explores the north American coastline

(1609) Henry Hudson sails into Newark Bay – the English would not sponsor his expedition – he requests and receives funding from the Dutch - he claims the land for the Dutch and names it New Netherlands

(1638) The Swedish establishes a colony along the lower Delaware River

(1660) The Dutch settles Bergen, the first permanent town

(1664) The British take control of New Netherlands from the Dutch and rename it New Jersey

(1787) New Jersey becomes the third US state

(1790) New Jersey becomes the first state to sign the Bill of Rights

(1838) Samuel Morse, a New Jerseyite, demonstrates the telegraph
A Brief History of New Jersey
(continued)

(1879) Thomas Alva Edison invents the incandescent lamp
(1884) Grover Cleveland, a New Jerseyite, is elected US President
(1912) New Jersey Governor, Woodrow Wilson, is elected US President
(1937) The Hindenburg crashes at Lakehurst Naval Air Station killing 35 people
(1993) Christine Todd Whitman becomes the first female Governor of New Jersey
(2001) United Airlines Flight 93 leaves Newark on 11 September and crashes into a field near the Diamond T Mine in Stonycreek Township, Pennsylvania, killing 33 passengers, 7 crew members, and 4 hijackers
(2007) New Jersey becomes the 3rd US state to offer civil unions to same-sex couples
(2007) The death penalty is abolished
A Famous New Jerseyite
Felix the Cat

Felix the Cat is a funny animal cartoon character created in the silent film era. The anthropomorphic black cat with his black body, white eyes, and giant grin, coupled with the surrealism of the situations in which his cartoons place him, combine to make Felix one of the most recognised cartoon characters in film history. Felix was the first character from animation to attain a level of popularity sufficient to draw movie audiences. He is said to be created by Otto Messmer (a New Jerseyite) – but is owned by Australian cartoonist and film entrepreneur Pat Sullivan.
Other Famous Faces from New Jersey

Albert Einstein

Alfred Kinsey

Edwin Aldrin

Thomas Alva Edison

Guglielmo Marconi
Some More Famous Faces
of
New Jerseyites

Woodrow Wilson
Samuel Finlay Morse
Alice Stokes Paul
Welcome to The 5th IKCC Expanding Circles
In Supporting Kidney Cancer
Morristown, New Jersey

16th April 2015

Speaker: Deb Maskens (CAN)

Speaker: Joyce Graff (USA)

Special announcements

Over 20 Countries represented
Where are we? – Morristown, New Jersey
Vision, Mission and Values of the IKCC
Long-term Positioning of IKCC
IKCC started in 2009 with the first Conference in Frankfurt, Germany in 2010

We always use ‘bad’ English
There is no such a thing as a ‘stupid’ question

IKCC
International Kidney Cancer Coalition

Julia Black knows EVERYTHING!
Julia Black can do EVERYTHING!
Markus Wartenberg

VERY LITTLE CAN BE SAID – What would IKCC do without you?
Legal Founding of IKCC

Signing of IKCC Deed on 9 December 2014
Mr Robert Collenteur (Notary)
Official Sponsors of IKCC

Bayer Healthcare

Bristol-Myers Squibb

Novartis Oncology

Pfizer Oncology

IKCC
International Kidney Cancer Coalition
The IKCC Board of Directors

- Dr Rachel Giles (Netherlands) Chair
- Deb Maskens (Canada) Vice Chair
- Anne Wilson (Australia)
- Prof Michael C Herbst (South Africa)
- Berit Eberhardt (Germany)
- Joyce Graff (United States)
- Rose Woodward (United Kingdom)
Kidney Cancer Updates for 2015

Moderator: Joyce Graff (USA)

Patient Perspective
Speaker: Denis Brezillan (FRA)
Rendered a valuable patient’s perspective to Kidney Cancer

Surgical Oncology
Speaker: Dr Gennady Bratslavsky (USA)
Surgery is the main curative treatment option with nephron sparing and functional preservation as priority – it forms an integral role in disease management

Medical Oncology
Speaker: Dr Jonathan Coleman (USA)
Comprehensive Oncology Care through a multidisciplinary team
Clinical Trials - the pathway to improving care
The value of targeted therapy in cancer
Keynote Address

Moderator:  
Dr Rachel Giles (NL)

Speaker: Dr Harold Varmus (USA)

An American Nobel Prize-winning scientist and the 14th Director of the National Cancer Institute, a post he was appointed to by President Barack Obama. He was a co-recipient (along with J Michael Bishop) of the 1989 Nobel Prize in Physiology or Medicine for discovery of the cellular origin of retroviral oncogenes

- Cancer and other NCDs are emerging as targets for improving global health
- Tobacco, obesity and alcohol - global health issues
- Human Papilloma Virus (HPV)
- A balanced and integrated approach to prevention, early detection and treatment is required to win the fight against cancer
Sharing Best Practices in Kidney Cancer Support & Advocacy

Moderator:
Rose Woodward (UK)

James Whale Fund for Kidney Cancer (United Kingdom)
Launch of a Kidney Cancer Buddy System in the United Kingdom

VHL Alliance (Ireland)
Supporting VHL patients and educating health professionals

V Care (India)
Administration of a Sutent Patient Assistance Programme

The Judy Nicholson Foundation for Kidney Cancer Research (USA)
Reducing pain, suffering and death associated with kidney cancer through research, education and support

Kidney Health (Australia)
Effective management and promotion of a kidney cancer project in line with organisational domains, namely: education, advocacy, research, support and information
Global Kidney Cancer Patient Charter

The IKCC Global Kidney Cancer Patient Charter was published in the Journal European Urology 0302-2838/# 2014

Evaluation of the ten (10) Patient Charter Rights in countries represented at the 5th Expanding Circles in Supporting Kidney Cancer Conference
How can Kidney Cancer Patient Groups Best Address Psychosocial Issues?

**Speaker: Kathleen M Nugent (USA)** – Clinical Social Worker
Patient Groups should provide:
- Counselling
- Support
- Educational workshops
- Financial support

**Discussion Panel**

*Timo Koponen* – The Association for Finnish Cancer Patients (Finland)

*Vandana Gupta* – V Care Foundation (India)

*Karen McNee* – James Whale Fund for Kidney Cancer (United Kingdom)
Day 2
Friday, 17th April 2015

We started the early morning session with a ‘picnic’ breakfast!
Information Session
Joining the IKCC as an Affiliate or Associated Individual

Moderator: Anne Wilson (AUS)
Facilitator: Markus Wartenberg (DE)

Affiliate Organisation
Associated Individual
Supporter

Overview and History
Involvement

IKCC Foundation
Sharing Information

Common Position
Different Types of Membership

Access to Treatment
Vision and Mission

IKCC Values
Joining Forces

Legal Entity
International Networking

An Organisation of Organisations
Strengthening Networks

Objectives
Activities
Projects

IKCC as a Coalition
Joining Forces with Stakeholders

A Global Voice
Patient Perspective: The **Barry Hoeven** Story (United States)
Diagnosed 1998 - radical surgery – eventually metastasised to lungs and bones – currently a 17 year survivor.

Surgical Oncology Perspective: **Dr Gennady Bratslavsky** (United States)
Made some important disclosures! All kidney cancers are not the same – it is like a bowl containing different fruit – it is heterogeneous. Explained the real role of a surgeon with some emphasis on the 3cm rule.

Medical Oncology Perspective: **Dr Ram Srinivasan** (United States)
RCC is a heterogeneous group of malignancies – some forms are very aggressive. Concentrated on Targeted Therapy for Metastatic Papillary RCC.
Kidney Cancer, Kidney Disease and the Role of the Nephrologist

Speaker: **Prof Allan J Collins** (United States)
Intersection between nephrology, medical oncology, surgical oncology.
Kidney sparing surgery – glomerular filtration rate.
Importance of sodium intake. Risks increase with decreasing kidney function.

Patient Perspective – **Frederick L Atkin** (USA)

Kidney Disease Organisation – **Carlos Castro Sanchez** (Mexico)

Kidney Cancer Specialist – **Dr Fabio A B Schutz** (Brazil)
Marketplace Session
Capacity Building & Organisational Issues

Working in a non-profit organisation: funding top level research – Alison Hahn (United States)

Building effective relations with medical experts – Kirren Grennan (Australia)

Using surveys, online polls and databases to learn more about your patient needs – Ilene Sussman (United States)

Using social media strategically to further your organisation’s goals – Bryan Lewis (United States)

Working with the pharmaceutical industry on projects – Eva Maria Ruiz de Castilla (Peru)
Drug and Treatment Access in Emerging Countries
Focus on Latin America

Moderator: Prof Michael C Herbst (ZA)

Speaker: **Dr Fabio A B Schutz** (Brazil)
There are major differences in epidemiology between Latin American (LA) and other more developed countries.
Top 4 cancers in LA: Prostate; Breast; Colorectal; and Lung.
Kidney cancer is 17th on the list in LA.
Patients often have to sue governments in LA to gain access.

**Discussion Panel**

**Luiza Cecilio** – Instituto Oncoguia (Brazil)
Access is a major problem.

**Juanita Ruiz** – Foundacion SIMMON (Colombia)
Patients struggle to gain access.

**Carlos Castro Sanchez** – Asociacion Ale IAP (Mexico)
No money – reduced access.

**Eva Maria Ruiz de Castilla** – Esperantra (Peru)
Patients do not get what they deserve.
External Dinner - Chef Fredy’s Table
Day 3
Saturday, 18th April 2015

We again commenced the day by enjoying a ‘picnic breakfast’ during the early morning session

More delegates attended the early morning session than on Day 2
USA Perspective – **Dr Kent Bottles** (United States)

Emphasis now on:
‘Wellness’ instead of ‘Sickness’ and ‘Acute disease to Chronic disease’
‘Hospital centric’ to ‘Community centric’ - ‘Doctor centric to Patient centric’
‘Doctor decides’ to ‘Shared decision making’

China Perspective – **Zhenxi Zhong** (China)

In China there are structures known as a ‘GONGO’ – this means Government Organised NGO! No pictures in presentation – cannot expose individuals to possible ridicule.

Government remains suspicious about structures that are not ‘controlled’.

Drs overworked and underpaid: very little time for face-to-face contact. There can be long waiting times before seeing a doctor. There is scope for corruption within the medical care system
Keynote Address: 
How Healthcare Systems are Beginning to Listen

Moderator: 
Dr Rachel Giles (NL)

Dave deBronkart  (United States) - “e-Patient Dave” - Stage IV kidney cancer survivor

Providers should not tell us that they believe we need to know – it is all about the patient’s perspective - “what is important to the patient”.

My story started following an X-ray showing a ‘spot’ on my right lung (stage IV).

My health data belongs to me.

We can all do better if we have access to health information.
Clinical Trials in Immuno-Oncology (Patient Perspective)

Peggy Zuckerman (United States)
11-year Survivor of Stage IV RCC – and is a patient advocate.
Had the desire to see her youngest son graduate from primary school – will after this weekend be having lunch with him, who now is a young man.
Patients should be provided with all relevant information regarding themselves.
Advances in Immuno-Oncology for Kidney Cancer

Moderator:
Deb Maskens (CAN)

Dr Janice P Dutcher (United States)
Immune response requires the ability of the immune killer cells to recognise the target – use of antigen-presenting cells.
It also requires the killer cells to kill – can be activated by a number of protective mechanisms.
Provided overview of Clinical Trials.
IKCC Global Projects for 2015/2016

Ongoing
- Dissemination of the Kidney Cancer Patient Charter
- Redesign of the IKCC Website
- Quarterly Newsletter, Social Media
- IKCC-Survey to Affiliated Organisations

Other activities/services/projects – without direct 2015 budget implications
- Early detection of Hereditary KC – understandable patient information
- Start in late 2015: Information to share. Different Profiles of Kidney Cancer Subtypes
- Position Paper on “Unmet Medical Needs in Kidney Cancer”
- Position Papers on “Bone Mets” and “Brain Mets”
- Strengthening the IKCC Global Network by encouraging the creation of new groups (Kidney Cancer, Kidney Disease, VHL-Groups, Other Cancers (Rare, General, Urogenitoury)
Participating in important Conferences and Networking Initiatives
(...if no grants/scholarships are available...)

- Important Oncology-, Urology-, Kidney Cancer Meetings/Conferences
- Cancer Patient Advocacy Meetings/Conferences
- Initiatives where IKCC is involved
- Travelling Expenses to meet different Stakeholders e.g. KC Medical Experts, Medical Societies, Sustaining Partners (Industry)
- Occasions to generate information or initiate collaborations
- Training/Education for LT-Members
Task Force/Consensus Roundtable “Papillary KC”

- Hosting the 1st IKCC Task Force/Roundtable bringing leading KC experts and KC patient experts together...
- Discussing spec. unmet medical needs in Kidney Cancer
  - to follow the patients pathway
  - to identify the gaps/problems/challenges
  - to clarify who is working / doing research on spec. topics
  - to come up with ideas/solutions/recommendations
  - to disseminate/publish the common findings
  - to generate follow up projects – if necessary/helpful
- Potential part of the AGENDA: To invite pharma companies presenting their ideas/concepts reg. future treatment options
- 1st IKCC Task Force/Roundtable will focus on “Papillary KC” Ideally “Recommendations for diagnosis, treatment and follow up with lead to a “paper/publication” in a scientific journal
- These 1-day meeting should be linked to intl. KC-meetings/ be cost- and time-effective for all participants…
Book of Courage and Hope (Global Patient Stories)

- A Book (Collection of) Kidney Cancer Patient Stories from around the world (+ Short Profiles of IKCC Affiliated Organisations)
- Target Audience: Pharmas, Medical Experts, Researchers, Regulators, Payers, Patient Adv. Groups, Patients with English Skills
- An image tool to transfer the power of the global kc patient advocacy
  - To communicate KC as a significant global health issue
  - To show the unity and diversity of the coalition
  - To promote the national KC patient advocacy/support groups (our Affiliated Organisations)
  - To clarify the role and services/performance of kc patient groups
  - To display the challenges, courage and hope of patients worldwide
Understanding clinical trials and immuno-oncology for kidney cancer...

Entenda ensaios clínicos e imuno-oncologia para o câncer de rim...

Capire le sperimentazioni — cliniche e immuno-oncologia per il cancro del rene...

Begrijpen klinische proeven en Immuun-Oncologie voor nierkanker...

Entender los ensayos clínicos y la inmunoo-oncología para el cáncer de riñón...

Понять клинические испытания и иммuno-onkологии рака почки

Comprendre les essais cliniques et immuno-oncologie pour le cancer du rein...

Klinische Studien und Immun-Onkologie bei Nierenkrebs verstehen...

Zrozum, badań klinicznych i immunologicznym onkologiczną raka nerki

कैंसर के रेनों के लिए क्लिनिकल प्रूफिज़न और इम्यूनो-ऑन्कोलॉजी की समझना

- NEW in 2015: IKCC Activity Report
- Target Audience: Pharmas, Medical Experts, Researchers, Regulators, Payers, Patient Adv. Groups, Patients with English Skills
- Contains our Projects, Activities, Engagement
- Overview Global KC Community (Image Tool)
- Will also include “Conference Report” from our Annual Conference 2015 in Morristown
- Available as PDF and a limited number of printed copies
- Release: Summer 2015
Travel Safely!
That's all Folks!