EXPANDING CIRCLES in Supporting Kidney Cancer

Morristown, New Jersey - U.S.A., 16th to 18th April 2015

5th International Conference for Organisations Representing Patients with Kidney Cancer



AGENDA

DAY 1 – Thursday 16 th April 2015		
09:00 - 09:15	START OF THE CONFERENCE	
	Welcome To The 5th IKCC EXPANDING CIRCLES In Supporting Kidney Cancer	
	- Special Announcement	
	Speakers: Joyce Graff (USA) & Deb Maskens (CAN)	
09:15 - 10:45	Moderator: Joyce Graff (USA)	
	Kidney Cancer - Updates for 2015	
	Patient Perspective - Speaker: Denis Brezillon (FRA)	
	 Surgical Oncology - Speaker: Dr. Gennady Bratslavsky (USA) Medical Oncology - Speaker: Dr. Jonathan Coleman (USA) 	
	Q & A Session	
10:45 – 11:15	TEA/COFFEE BREAK (30 minutes)	
11:15 – 12:00	Moderator: Dr. Rachel Giles (NL)	
	Keynote Address: Cancer Challenges in Mexico and the Global Perspective	
	Speaker: Dr. Harold Varmus (USA), Director of the National Cancer Institute and co-	
	recipient of a Nobel Prize (1989) for studies of the genetic basis of cancer.	
	Q & A Session	
12:00 - 13:30	LUNCH (90 minutes)	
13:30 – 15:00	Moderator: Rose Woodward (UK)	
	Sharing Best Practices In Kidney Cancer Support & Advocacy	
	James Whale Fund for Kidney Cancer, UK	
	VHL Alliance V One Foundation India	
	V Care Foundation, India The Judy Nicholson Foundation for Kidney Cancer Research, USA	
	Kidney Health Australia	
	Q & A Session	
15:00 – 15:30	Moderators: Deb Maskens (CAN) & Dr. Rachel Giles (NL)	
	Global Kidney Cancer Patient Charter	
	Speaker: Dr. Rachel Giles (NL)	
15:30 – 16:00	TEA/COFFEE BREAK (30 minutes)	
16:00 – 17:30	Moderator: Robin Martinez (USA)	
	How Can Kidney Cancer Patient Groups Best Address Psychosocial Issues?	
	Speaker: Kathleen M. Nugent, Licensed Clinical Social Worker (LCSW) (USA)	
	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, UK	
	Q & A Session	
BREAK BEFORE DINNER (90 minutes)		
19:00 – 23:00	Conference Welcome Dinner and Networking	
	Concord Room, Hyatt Morristown at Headquarters Plaza	

DAY 2 – Friday 17 th April 2015		
07:30 - 08:30	Early Breakfast Session (optional)	
	Facilitators: Anne Wilson (AUS) & Markus Wartenberg (DE)	
	Information Session: Joining the IKCC as an Affiliate or Associated Individual	
8.30 - 09.00 I	BREAK BEFORE MAIN CONFERENCE (30 minutes)	
09:00 - 10:30	Moderator: Deb Maskens (CAN)	
	Challenges and Opportunities for Non Clear Cell RCC	
	Patient Perspective - Speaker: Barry Hoeven (USA)	
	Surgical Oncology Perspective - Speaker: Dr Gennady Bratslavsky (USA)	
	Medical Oncology Perspective - Speaker: Dr. Ram Srinivasan (USA)	
	Q & A Session	
10:30 - 11:00	TEA/COFFEE BREAK (30 minutes)	
11:00 – 12:30	Moderator: Anne Wilson (AUS)	
	Kidney Cancer, Kidney Disease and the Role of the Nephrologist:	
	Speaker: Prof. Allan J. Collins (USA)	
	Discussion Panel:	
	Patient Perspective – Frederick L. Atkin (USA)	
	Kidney Disease Organisation - Carlos Castro Sanchez (MEX) Kidney Organization - Par Fathic A. B. Ochora (REA)	
	Kidney Cancer specialist – Dr. Fabio A. B. Schutz (BRA) O 8 A Canadan	
40.00 44.00	Q & A Session	
<u>12:30 – 14:00</u>	LUNCH (90 minutes)	
14:00 – 15:30	The Marketplace Session	
	Capacity Building and Organisational Issues For Patient Groups	
	Delegates may choose a maximum of 3 sessions to attend from the following topics:	
	Marking in a non-profit arganization, funding ton level research	
	Working in a non-profit organisation: funding top level research Alison Hahn (USA)	
	Building effective relations with medical experts	
	Kirren Grennan (AUS)	
	Using surveys, online polls and databases to learn more about your patient needs Ilene Sussman (USA)	
	Using social media strategically to further your organisation's goals	
	Jay Bitkower & Bryan Lewis (USA)	
	Working with the pharmaceutical industry on projects Fig. Marie Pair de Contille (DER)	
	Eva Maria Ruiz de Castilla (PER)	
	Each session 20 minutes duration: 10 minutes presentation with 10 minutes Q & A.	
15:20 16:00	At the end of the session, delegates move onto their next chosen session.	
15:30 – 16:00 16:00 – 17:30	TEA/COFFEE BREAK (30 minutes) Moderator: Prof. Michael Herbst (ZA)	
10.00 - 17.30	Drug and Treatment Access in the Emerging Countries (Focus on Latin America)	
	Speaker: Dr. Fabio A. B. Schutz (BRA)	
	Discussion Panel:	
	Luiza Cecilio - Instituto Oncoguia, Brazil	
	Juanita Ruiz - Fundación SIMMON, Colombia	
	Carlos Castro Sanchez - Asociación Ale IAP, Mexico	
	Eva Maria Ruiz de Castilla - Esperantra, Peru	
	Q & A Session	
BREAK BE	FORE DINNER (90 minutes)	
19:00 – 23:00	External Dinner – Chef Fredy's Table	
75.55 25.50	Please meet in the hotel reception at 19:00	
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DAY 3 – Saturday 18 th April 2015		
07:30 - 08:30	Early Breakfast Session (optional)	
	Moderator: Joyce Graff (USA)	
	Doctor/Patient Communication:	
	USA Perspective - Speaker: Dr. Kent Bottles (USA)	
	China Perspective - Speaker: Zhenxi Zhong (CHN)	
	Q & A Session	
8.30 - 09.00 BREAK BEFORE MAIN CONFERENCE (30 minutes)		
09:00 - 09:45	Moderator: Dr. Rachel Giles (NL)	
	Keynote Address: How Healthcare Systems are beginning to Listen	
	Speaker: Dave deBronkart (USA), 'e-Patient Dave', stage IV kidney cancer survivor; now	
	the Mayo Clinic's 2015 visiting Professor in Internal Medicine	
	Q & A Session	
09:45 – 11:00	Moderator: Deb Maskens (CAN)	
	Clinical Trials in Immuno-oncology (patient perspective)	
	Speaker: Peggy Zuckerman (USA)	
	Advances in Immuno-oncology for Kidney Cancer	
	Speaker: Dr. Janice P. Dutcher (USA)	
	Q & A Session	
11:00 – 11:30	TEA/COFFEE BREAK (30 minutes)	
11:30 – 12:15	Moderators: Deb Maskens (CAN) & Markus Wartenberg (DE)	
	IKCC Global Projects for 2015/2016	
	Speakers: Deb Maskens (CAN) & Markus Wartenberg (DE)	
12:15 – 12:30	End Of Conference, Summary, Feedback-Forms, Closing Remarks,	
	Thanks To The Presenters & Sponsors	
	Speakers: Anne Wilson (AUS) & Prof. Michael Herbst (ZA)	
12:30	OFFICIAL END OF THE CONFERENCE	

Conference Venue:

Hyatt Morristown at Headquarters Plaza□

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