



"Breaking the barriers for patients"

Wednesday, January 21, 2015

Location: **De Nederlandsche Bank, Westeinde 1, Amsterdam.**

Welcome dinner: "Breaking the barriers for patients"

18.00 – 19.00 Drinks

19.00 – 21.30 Diner

Thursday, January 22, 2015

Location: **Royal Netherlands Academy of Arts and Sciences, Kloveniersburgwal 29, Amsterdam**

09.00 - 09.30 Registration with coffee and tea

09.30 - 09.45 Welcome by the Conference Chairs – Piarella Peralta (I2L) and
This is our Manifest! Fred Verdult (Volle Maan)

09.45 - 9.55 Welcome: Royal Netherlands Academy of Christine Mummery on behalf of KNAW
Arts and Sciences

09:55 - 10:25 *AIDS Activism of ACTUP in the nineties* Corinna Gekeler (former activist and
political scientist)

10.25 - 11.00 Pecha Kucha Gaston Remmers (I2L)
We have to prevent the Titanic from hitting
the iceberg – Reducing Incidence: Stay healthy if
you can Nicoline Hoogerbrugge, Radboud Univ.

11.00 - 11.30 Break

11.30 - 12.05 Pecha Kucha Veronica van Nederveen (I2L)
'Regulatory Challenges: an area for campaigns?' David Townend, University of Maastricht
Quality of Care - It's all about good governance
and the right culture)

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12.05 - 12.40	Pecha Kucha "How are you feeling?" "Who wants to know?" – <i>Quality of life assessment in cancer clinical research and clinical practice</i> – Quality of Life – <u>Quantity over Quality?</u>	Geert Bakker (I2L) Neil Aaronson, The Netherlands Cancer Institute
12.40 – 13.45	Lunch	
13.45 – 15.15	Breakout sessions. What can we do to break down the barriers and improve our Manifest: 1. Reducing Incidence 2. Quality of Care 3. Quality of Life, co-chair	Nicoline Hoogerbrugge and PA Gaston Remmers, I2L David Townend and PA Veronica van Nederveen, I2L Neil Aaronson and PA Geert Bakker, I2L
15.15 – 16.45	Second breakout sessions: Join another group!	
16.45 – 17.45	Plenary Feedback and discussion of the breakout sessions, actions to the Manifest	
17.45	Walk to the restaurant (The Grand, Oudezijds Voorburgwal 197, Amsterdam)	
18:00	Drinks	
19.00 – 21.30	Dinner with a speech (through video) on Advocacy	Peter Staley, former activist, ACTUP

Friday, January 23 2015

Location: **Royal Netherlands Academy of Arts and Sciences, Kloveniersburgwal 29, Amsterdam**

08.30 - 09.00	Registration with coffee and tea	
09.00 - 09.10	Welcome by the conference chairs	Piarella Peralta and Fred Verdult
09.10 - 09.20	Welcome: Central Bank of the Netherlands	Alexander Rinnooy Kan on behalf of Dutch Central Bank
9.20 – 9.50	How to be disruptive: The role of "Appropriate Irreverence" (NL: gepaste oneerbiedigheid)	Stephen Friend, CEO Sage Bionetworks
09.50 - 10.25	Pecha Kucha <i>It's urgent to improve efficiency in bench to bedside Innovation of the Clinical Practice - If I were a mouse <u>I would have been cured years ago</u></i>	Seun Adebisi (American Cancer Society) Sabine Tejpar, University of Leuven.

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10.25 – 10.55	Break	
10.55 – 11.30	Pecha Kucha <i>Responsibility and Regulation</i> - Early access to drugs - <u>Tantalus torture: we have drugs but we can't have them!</u>	Ingemar van der Molen (film) (I2L) Jessica Flanigan, Univ. Richmond, USA
11.30 – 13.00	Breakout sessions. What can we do to break down the barriers and improve our Manifest: 4. Innovation of the Clinical Practice 5. Early access to drugs 6. How to be disruptive?	Seun Adebisi and PA Kees Braam (I2L) Jessica Flanigan and PA Ingemar van der Molen Stephen Friend and PA Ilona Schelle
13.00 – 14.00	Lunch	
14.00 - 14.30	I am a Patient Advocate by necessity	Bettina Ryll, Researcher and PA Upsalla University
14.30 – 16.00	Second breakout sessions: Join another group!	
16.00 – 17.00	Plenary Feedback and discussion of the breakout sessions, actions to the Manifest	
17.00 – 17.15	Wrap up by the chair Piarella Peralta	
17.15	End of the conference, followed by an informal buffet at the Royal Academy building	
18.30	Closing of the buffet	

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