



"The countless small deeds of the unknown people "

The Inspire2Live 2018 Annual congress

February 7 (diner), 8 and 9 - 2018

'What really matters are the countless small deeds of unknown people who lay the basis for the events of human history. These are the people who have made change in the past; they are responsible for making change in the future, too.'

(Noam Chomsky, American Philosopher, in 2015 documentary Requiem for the American Dream, Chomsky paraphrasing his late friend, the historian Howard Zinn).

Wednesday, February 7, 2018

Location: 'Restaurant Brooklyn', NDSM Wharf, NDSM-Plein 30, Amsterdam
(If you take the Ferry take the one to NDSM Werf.)

18.00 – 19.00 Drinks & welcome by Inspire2Live Patient Advocate Linda Burger

19.00 – 21.30 Welcome dinner

Opening speech by Erik Gerritsen, Secretary General Dutch ministry of health.

Thursday, February 8, 2018

Location: 'Under Current', NDSM Wharf, Papaverweg 265, 1032 KE Amsterdam
If you take the Ferry take the one to 'NDSM Werf'.

08.45 - 09.15 Registration with coffee and tea

09.15 - 9.30 Welcome by the conference chairs

Rebecca Malby (London South Bank Univ)
& Piarella Peralta (Inspire2Live)

9.30 – 10.00 How laypeople can contribute to scientific advancement: my journey with the Nigerian bone marrow registry

Seun Adebisi (Bone marrow registry)

10.00 – 10.30 The collaborative advantage of ecosystems

Annemieke Roobeek
(Meeting More Minds)

10.30 – 11.00 Coffee, tea and networking

11.00 – 11.30 Designing Tools for Navigating between our Health and Disease: Symptom Predictions and Return of Agency

Stephen Friend (Sage)

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11.30 – 12.15 Rapid fire talks of participants.

What happened in my organization? What did we realize to change and how did we do it?
In speed presentations of 5 minutes inspirational participants talk about their way of refurbishing the organization they are part of.

Isaac Bullock Kintu (Accenture), Willem Ernst Herter (Pacmed), Marta Fernandez (Fundacion Josep Carreras), Barbara Moss (Colon Cancer UK), Tim van Veenendaal (Manus VR), Susan Gabriëls, Tjebbe Tauber (Inspire2Live).

12.15 – 13.00 Panel discussion:

'Why did we realized this change and how?' Ian Banks (vice President ECC)

Panel members: Seun Adebisi (Bone marrow registry), Maurice Wiegman (Passiezonderbeperving), Natacha Bolaños (Lymphoma Coalition Europe) & Ronald Brus (myTomorrows).

13.00 – 17.30 Take away lunch and groups at work in breakout sessions.

Group A: *'Empathy is what can – will – change the world. Simulation is the best way to get a point across, especially to children.'* This group stays at Under Current and participates in a workshop lead by medical doctor Parag Mankeekar (Neetisolutions–Mumbay) & Ilona Schelle.

Group B: *'The need for randomized trials: can we accelerate the translation of novel targeted and immunotherapies to the clinic?'* This group visits the VUMC/Cancer Center Amsterdam and works with prof. dr. Bob Pinedo, prof. dr. Tanja de Gruij & prof. dr. Rik Scheper & Margot Kitzen

Group C: *'The healthy city of Amsterdam'*. This group visits the 'Huis van de Wijk de Evenaar' in Amsterdam Noord and works with prof. dr. Jaap Seidell, Mark Vlaar & Barbara van Kesteren.

Group D: *'What is the role of (healthy) gut flora in the prevention and treatment of cancer?'* This group visits Winclove probiotics in Amsterdam Noord and works with Maarten Pekelharing & Guan Schellekens.

Group E: *'Children with cancer and the need of patients and their parents'*. This group visits the VUMC and works with prof. dr. Gert Jan Kaspers (Children Hospital) & Jozef Duivesteijn.

17.30 – 18.00 Report back and presentations of the plan of actions by the groups

18.30 – 21.30 **Diner at 'Restaurant Brooklyn', NDSM Wharf, NDSM-Plein 30, Amsterdam (If you take the Ferry take the one to NDSM Werf.)**

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Music performed by patient advocate Mark Moss.

Presentation of the Inspire2Live Patient Advocate Hero of Cancer Award.

Friday, February 9 2018

Location: 'Under Current', NDSM Wharf, Papaverweg 265, 1032 KE Amsterdam
If you take the Ferry take the one to NDSM Werf.

8.30 - 9.00	Registration with coffee and tea	
9.00 – 9.15	Welcome by the conference chairs	Rebecca Malby & Piarella Peralta
9.15 – 9.30	Change in Amsterdam – how is it done?	Erik Teunissen (Dutch Central Bank)
9.30 – 10.00	Data is a gift. Deal with it that way	Kadija Ferryman (Data & Soc. Res. Inst.)
10.00 – 10.30	How unknown people take agency over their data? (Introduction to the beginners mind sessions)	Gaston Remmers (Inspire2Live)
10.30 – 11.00	Beginners mind & experienced hand, ETH, Zürich	Ernst Hafen (ETH, Zürich) + beginners minds
11.00 – 11.30	Beginners mind & experienced hand, University of Aberdeen	James N'Dow (Univ. Aberdeen) + beginners minds
11.30 - 12.00	Coffee, tea and networking	
12.00 – 12.30	Beginners mind & experienced hand, ErasmusMC, Rotterdam	Dik van Gent (ErasmusMC) + beginners minds
12.30 – 13.00	Beginners mind & experienced hand, Neetisolutions, Mumbai	Parag Mankeekar (Neetisolutions) + beginners minds
13.00 – 16.00	Take away lunch and groups at work in breakout sessions.	
16.00 – 16.30	Report back and presentations of the plan of actions by the groups	
16.30 – 17.00	Reflections – end of conference	Ilona Schelle & Peter Kapitein

Background and content of the congress.

Daily we see that healthcare is distracted from its essence: the patient. The change will come from the citizens and the patients: *'the countless small deeds of unknown people.'* Each and every one of the stakeholders is a citizen whose actions in the present will consequently reflect into our future. It is time that we not only look into ways on how to improve the practices in our own fields of health care, but also look into ways on how to influence

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it into a sustainable health fostering system that embraces universal access. Inspire2live departs from its traditional way of working where actions are taken up *after* the congress. By building momentum and engaging our multi-stakeholder, multi-generational and interdisciplinary partners into thinking and dreaming of ways in which we fundamentally shift from traditional frameworks and paradigms within cancer care into sustainable societies of health *before* the congress. As a way of going back to the beginning of 'Understanding Life' (also the name of the program of Inspire2Live to get cancer under control) and building upon life and health as a movement of the citizens and patients, we invite young academics with an experienced researcher to reflect on Inspire2live's assignment for the congress. They reflect and *combine their beginners mind with the experienced hands*.

There is a tendency in the public debate to point to 'our' responsibility to fulfill the goals regarding the approach to health and health care in our societies. This year we introduce an important term when discussing issues regarding our approach to health: '*agency*'. The need to switch this view is to depart from archaic, traditional ways of approaching health and health care in all of its dimensions from the initial stage of research and developing treatments to policy making and implementation. It is important to depart from a static responsibility to a more dynamic approach in which we; the citizens and patients have the possibility to exercise our right to be engaged in all these processes that have such great impact in our daily lives.

As patient advocates we know that data holds the key into shifting not only our health practices but also into bringing back a symmetric relationship in health care. This data-topic is thus at the base of the different stages and dimensions of health care. Having individuals taking agency over their data is a more accurate way to conceive this future in health care and which goes beyond any duty or responsibility outside of the individual and points to a more dynamic approach to a fair system in health care: '*The patient will see you now*'. Making the shift in this realization may create greater possibility into building societies of health. Inspire2live feels it is important to bring explicitness to this concept, as it is a movement what we are referring to when we speak of "*the countless small deeds of unknown people*"

The assignment for the beginners mind and the experienced hands.

We have learned over the years that the actions and observations of patients and citizens are crucial. Their data are crucial. How can these be put to value for themselves and health care at large? And how should we do that? And in what new way can citizen-driven data generation be joined with new forms of data-governance, research and responsible business? With this in mind, at the occasion of the Inspire2Live congress we ask *beginners minds and experienced hands*, to reflect on the empowerment of the countless small deeds for the sake of the health system. In the India, Switzerland, the UK and the Netherlands. We've formulated these 3 questions:

- What practices do you see/dream/hope within your field of expertise and within your geographical area, as key examples of engaging the public on data, that impulse a movement that will create a shift from the current focus of disease into health societies?
- What new combinations of citizen-driven data generation, data governance, research and responsible business are emerging or needed?
- What are steps that can be taken, and by who, that will make these practices applicable, in a way that citizens and patients remain in the driver's seat?

They reflect in the months preceding the congress and present their findings in the interactive sessions.

The result

The unknown people will influence the stakeholders in healthcare:

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- The citizen is inspired to stay healthy.
- We are determined to make ourselves healthy.
- The scientist creates a broad spectre, works with tons of data with which he can do endless research. The scientist is aware of the impact his work has on the quality of life of us and our loved ones.
- The doctor is listening and acting for us. The doctor is aware that he can only do a small part of what is necessary. The doctor evolves from god to guide and is aware that 'The patient will see her now'.
- The industry will only allow itself to make profits with products that benefit us.
- The health insurance company is in conversation with us and negotiate for us for the best treatments and the lowest costs.
- The government supports prevention (or acts preventively) and knows what to do.

January 31st, 2018

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