



"We want to be at the table and not on the menu!"

The Inspire2Live 2019 Annual Congress

January 30 (diner), 31 and February 1 – 2019

'Health is a matter of all citizens. The unborn, the young, the young adult, the adult and the elderly.' We have to take care that health is not only important when we get sick, when we are diagnosed with cancer. It matters always and it needs to be emphasized when we are still healthy.

Health deals with physical, social and psychological aspects in a healing environment.

In healthcare, when citizens have become a patient, we have to look at diagnoses, the planning of the treatment, the treatment, reintegration in society after treatment and the after care. For the patient and her loved ones. When citizens have not yet become patients we have to look at prevention.

Two more common themes in all these stages: data and quality of life (the neglected child in healthcare economics and trials). This also plays a fundamental role in the patient's journey from citizen to patient to citizen.

We need activist interventions immediately after we know the state of the art and what is still needed.

We patient advocates demand that our health is taken seriously by government and industry and by society as a whole. Citizens, patients and patient advocates are responsible for our health.

We better start thinking, discussing and working on it now. We want to be at the table. Not on the menu!

Wednesday, January 30, 2019

Location: 'De Nederlandsche Bank, Westeinde 1, Amsterdam

16.00 – 17.00 Drinks & welcome

17.00 – 17.45 I want to share my story with you Jason van der Burgt (I2L)

17.45 – 18.15 The help of Artificial Intelligence for patients Tjebbe Tauber (I2L)

18.15 - 18.45 How industry as enabler can benefit the patient Jan Kimpen (Philips)

18.45 – 21.30 Welcome dinner

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Thursday, January 31, 2019

Location: 'De Nieuwe Liefde', Da Costakade 102, 1053 WP Amsterdam
<http://denieuweliefde.com>

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 Our health and societal change
Mary Baker (European Brain Council)

10.00 – 10.30 We deliver the best care for children
Rob Pieters (Prinses Maxima Children Hospital)

10.30 – 11.00 Economics of cancer systems across Europe: affordability and value
Richard Sullivan (Kings College)

11.00 – 11.30 Coffee, tea and networking

11.30 – 12.00 Navigating between health and disease
Stephen Friend (Sage Bionetworks & 4YouandMe)

12.00 – 12.45 Rapid fire talks of participants.

What happened in my organization? What did we realize to change and how did we do it?
In 8 speed presentations of 3 minutes and 1 slide at the max inspirational participants talk about their way of refurbishing the organization they are part of.

Pouya Zarchin, Lotte Reinhoudt, Noortje Gabriëls, ...

12.45 – 13.30 Public discussion: 'Why don't we implement in society for our health what we want and what we can?'
Lead by Rebecca Malby

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13.30 – 17.30 Out in the city.

Take away lunch and groups at work in breakout sessions somewhere in Amsterdam. The theme is: Wat is possible? What can be done?

Group 1: The evolution of the city Amsterdam	Amsterdam City Archive (Gert Eijkelboom)
Group 2: The Amsterdam Noord-Zuid metro: how did we realize it?	Amsterdam Public Transport (GVB)
Group 3: DNA-profiling as a standard.	Science Park - Hartwig Medical Foundation (Edwin Cuppen)
Group 4: The young ones A	Location TBD – Noortje Gabriëls (LUMC) and Lotte Reinhoudt (VUMC)
Group 5: The young ones B	Location TBD – Vedang Ranada (Poona) and ?

18.00 – 22.00 **Diner at 'to be decided' in Amsterdam**

18.30 – 19.00 Report back and presentations of the plan of actions by the groups

Music performed by prof. dr. Fritz Schröder.

Presentation of the Inspire2Live Patient Advocate Hero of Cancer Awards.

Friday, February 1, 2019

Location: **'De Nieuwe Liefde', Da Costakade 102, 1053 WP Amsterdam**
<http://denieuweliefde.com>

8.30 - 9.00 Registration with coffee and tea

9.00 – 9.30 Welcome by the conference chairs Rebecca Malby & Piarella Peralta

9.30 – 10.00 It's possible to change governments Jaykumar Menon (Centre for International Sustainable Development Law)

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10.00 – 10.30	We want our health and we want it now	Natacha Bolanös (Lymphoma Coalition)
10.30 – 11.00	Coffee, tea and networking	
11.00 – 14.00	Working sessions with lunch served during the sessions. Participants work with the leaders of the sessions towards a document with minutes, conclusions and advises on the topics. This is for Insprie2live the basis for writing a lobby document and start lobbying for this purpose.	
11.00 – 14.00	How to get the best <u>prevention</u> ?	Hanno Pijl (Leiden University Medical Center) and 2 patient advocates
11.00 – 14.00	How to get the best <u>diagnostics</u> ?	Peter Keeling (Diaceutics) and 2 patient advocates
11.00 – 14.00	How to get the best <u>treatments</u> ?	Mark Lawler (Queens University Belfast) and 2 patient advocates
11.00 – 14.00	How to get the best <u>after care</u> ?	Carmen Loiselle (McGill University Montreal) and 2 patient advocates
14.00 – 14.30	What do I take home from the congress?	6 participants
14.30	End of conference	Peter Kapitein

June 13th, 2018

Background and content of the congress.

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?

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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:

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.

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