



Moving the world for the global patient through reciprocity
Inspire2Live Annual Congress 2022, February 2, 3 and 4 at the Royal Society in Amsterdam

Julian Savulescu: 'To delay the development of a treatment that cures a lethal disease that kills 100.000 people per year is to be responsible for the deaths of those 100.000 people, even if you never seen them.'

The COVID-19 pandemic has affected all parts of the world. Solutions to the pandemic, such as vaccines, have, however, become available above all for the richer countries. The West has been reluctant to make the vaccines available at low cost for economically less powerful countries. Although it seems logical that the West first takes care of its own problems, it also shows a lack of solidarity and a consciousness of global interconnectedness: we can't do well if other countries don't.

In cancer research and care, we witness similar processes. The number of resources available for western countries is unparalleled compared to those in other parts of the world. So, it seems that cancer is much better treated than elsewhere. At the same time, the West is suffering from *inhibitory prosperity*. Because of regulation, the potential to improvise is lost. At the same time, in Africa, Latin America and Asia, access to excellent care is less taken for granted. Paradoxically, precisely in the global South unexpected ways of research and care have been developed that might be insightful for the West. In a way, the absence of means spurs the quality of being attentive to what might work. So, there is an openness to the unexpected.

In a way, in the absence of means, that give an illusion of control, the quality of being attentive to what might work, is present. Even if it means applying an n=1 approach to that patient's treatment and going beyond the randomized control trial constraints.

Inspire2Live is successful in all parts of the world. From Australia to South America, we have hubs with patient advocates and scholar activists. The Inspire2Live network is strong and many initiatives are taken or inspired by us. But we do far too little and not good enough. If we execute what we know, we can even improve the percentage of success. Probably, we could reach over 70%. There is a need to learn from each other as a global community, so that the best approach is taken for each patient, irrespective of where that person lives.

To that end, Inspire2Live designed and implements BUCS; Bottom-Up Cancer Support. Four Ps are crucial:

- Have a big focus on Prevention. 50% of all cancers can be prevented
- When you suffer from cancer at least take care of a good Performance: physicians and patients should act wise and skilful
- When suffering from Pain, have good pain-management
- And when there is Potential in something unexpected, use it

We know this can be achieved for all citizens of the world and is cheap. Everyone can afford it.

This Annual Congress highlights the innovative practices in all continents. The key questions that we will ask: 'What are the qualities of innovative practices in the represented countries that bear a learning for other countries?' and 'What can the different countries in the world contribute to each other and how can they make each other flourish to strengthen their capacities?' We are complementary to each other. To make it work, we need an attitude of *Reciprocity*. That is the keyword of the 2022 Inspire2Live Annual Congress.

never ever quit!

Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • www.inspire2live.org



Wednesday, February 2, 2022

Location: The Royal Netherlands Academy of Arts and Sciences, Het Trippenhuis, Kloveniersburgwal 29, NL-1011 JV Amsterdam, <https://www.knaw.nl/en>

- 16.00 – 16.45 Reception & drinks
- 16.45 – 17.00 Opening words by the director of the congress Ilona Schelle (I2L)
- 17.00 – 17.30 I'm a patient advocate by necessity Ghada Ibrahim (I2L)
- 17.30 - 18.00 The contribution of industry to patients globally Nibedita Rath (I2L and Open Source Pharma)
- 18.15 - 18.45 The contribution of physicians to patients globally Sarper Diller (Istanbul University & I2L)
- 18.45 - 19.15 The contribution of the WHO to patients globally Clement Chauvet (WHO/IARC) (TBC)
- 19.15 – 20.00 'The coalition of the willing' (a panel discussion)
When science says: 'This is how it is'. The doctors tell us: 'This is how we can treat our patients. And the patients say: 'This is how we want to be treated'. Who can then object and not facilitate the new approach of treating patients? Building a coalition of the willing goes before building the coalition of the ones who pull the strings. But how do you do such a thing on a global basis and have the low and middle income countries benefit as well?
- This panel is moderated by Rebecca Malby (London South Bank Univ.). The panellists are Ghada Ibrahim (I2L), Nibedita Rath, Sarper Diller and Clement Chauvet.
- 20.00 – 22.00 Welcome dinner and music (guitar) performed by Mark Moss (I2L)

Thursday, February 4, 2020

Location: The Royal Netherlands Academy of Arts and Sciences, Het Trippenhuis, Kloveniersburgwal 29, NL-1011 JV Amsterdam, <https://www.knaw.nl/en>

- 08.15 - 9.00 Registration with coffee and tea
- 9.00 – 9.15 I'm a patient advocate by necessity Piarella Peralta (I2L)
- 9.15 - 9.30 Welcome by the conference chairs Maureen Visscher & Tjebbe Tauber (I2L)
- 9.30 – 9.45 Welcome by the president of the Royal Netherlands Academy of Arts and Sciences Ineke Sluiter (KNAW)
- 9.45 – 10.15 It starts with cooperating for the benefit of Kwasi Boahene (PharmAccess) (TBC)

never ever quit!



- the ones that need it most
- 10.15 – 10.45 I'm a scholar activist by necessity Mark Lawler (Queens Univ. Belfast & I2L)
- 10.45 – 11.15 Coffee, tea and networking
- 11.15 – 12.00 Rapid fire talks of participants.
What happened in my life or my organization? What did I realize and how did I do it? In presentations of 3 minutes and 1 slide at the max inspirational participants talk about their way of refurbishing the organization, they are part of.
The session chair is Rebecca Malby.
- 12.00 – 12.30 Update on how digital devices might allow us to follow symptom transitions and the effects of the fabric of life on chronic conditions Stephen Friend (Sage & 4YouandMe)
- 12.30 – 13.00 A public discussion, chaired by Rebecca Malby
'What made me successful in changing my organization?'
- 13.00 – 13.30 Lunch, networking and preparation for 'Out in the city'.
- 13.30 – 17.30 Out in the city.
In 3 groups we travel through Amsterdam and visit interesting organizations and places.
Group 1: PharmAccess Kwasi Boahene
(PharmAccess) &
Ilona Schelle
Group 2: Tropenmuseum and Amsterdam tour Gert Eijkelboom (DNB) &
Nicole van Leeuwen (I2L)
Group 3: HMF Edwin Cuppen (HMF),
Hans van
Snellenberg (HMF) & Piarella Peralta
- 17.30 – 22.00 **Dinner at 'Hotel The Grand', Oudezijds Voorburgwal 197, 1012 EX Amsterdam**
<http://www.sofitel-legend-thegrand.com>
- 17.30 – 19.00 Drinks and report back 'Out in the city'
- 19.00 – 19.15 Presentation of the Inspire2Live Patient Advocate Hero of Cancer Awards.
So far, we awarded Bob Pinedo, Fritz Schröder, Pauline Dekker, Wanda de Kanter, Stephen Friend, Bob Weinberg and Laura van 't Veer for their contribution to patients. This year we will honour other researchers or clinicians with this advocacy award.
- 19.15 – 22.00 Dinner and music:
Cello, performed by Fritz Schröder (ErasmusMC) and

never ever quit!



Stephen Dedalus poems performed by Mark Lawler (Queens University)

Friday, February 5, 2020

Location: **The Royal Netherlands Academy of Arts and Sciences, Het Trippenhuis, Kloveniersburgwal 29, NL-1011 JV Amsterdam, <https://www.knaw.nl/en>**

8.15 - 8.45	Registration with coffee and tea	
8.45 – 9.00	Welcome by the conference chairs	Maureen Visscher & Tjebbe Tauber
9.00 - 9.30	Financial Stability and health for the global patient	Olaf Sleijpen (DNB) (TBC)
9.30 - 10.00	Dealing with oncology in Africa	Khama Rogo (retired World Bank repr. for Africa)
10.00 – 10.30	I'm a patient advocate by necessity	Salomey Eferemor (PECA & I2L)
10.30 – 11.00	Moving Early Diagnostics to global patients	Mao Mao (Seekin & I2L)
11.00 – 11.30	Coffee, tea and networking	
11.30 – 12.00	It starts with cooperating for the benefit of the ones that need it most	Andrew Trister (Bill & Melinda Gates Foundation)
12. 00 – 15.00	Working sessions, lunch included. Participants choose group A, B or C.	
Participants work with leaders of the sessions and under the direction of PA's, towards the answer to the question: ????		
15.00 – 15.15	What do I take home from the congress?	Participants chosen during the congress
15.15 -	End of conference – closing words	Ilona Schelle

never ever quit!

Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • www.inspire2live.org