



Moving the world for the global patient

Inspire2Live Annual Congress 2022, February 2, 3 and 4

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.'

50% of all the cancer patients can be prevented. Cancer is spreading over the world like an epidemic for decades. These 50% of cancer patients are an unbearable burden for society, as it is for the patient and their loved ones, therefore *'we have to prevent the Titanic from hitting the iceberg'* (Bob Weinberg). We do know however, that we have agency when it comes to our health. We can prevent ourselves from getting cancer. But what's preventing us from preventing?

In the Western countries, it seems that cancer is much better treated than elsewhere. At the same time, the West is suffering from inhibitory prosperity. Cancer research and care is so much regulated that innovative pathways for research and care are sometimes overlooked. In a way, the urgency and potential to improvise is lost. At the same time, in some countries in Africa, Latin America and Asia, access to excellent care is much 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, 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. 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.

Inspire2Live is successful in a great part of Europe. Our 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 in the Western world. Probably, we could reach a little over 70%. But we still do not execute what we know and when you do not execute what you already know, it's a bloody scandal (David Lane). What's preventing us?

We need all the stakeholders in the medical industrial complex to be successful in our global quest. When one of them acts alone we will not be successful, or it takes too long. We are building 'Inspire2Live Hubs'. Working groups of scholar activists and patient advocates that connect the stakeholders of the medical industrial complex. To put pressure where needed, to help where needed, so that we do right by the global patient.

We already have one hub in Europe and we start with hubs in Africa (to be arranged), Asia (Singapore), South and Middle America (Costa Rica), USA East Coast (Boston) and USA West Coast (San Francisco).

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 we can learn from each other?
- What can the different countries in the world contribute to each other to strengthen their capacities?
- How can we built the cooperation between the different countries and continents?

The core values of the congress are: Activism, Alertness, Vividness, Attentiveness and Sharing.

Our Annual Congress 2021 is about *'agency and epidemiology of cancer for the global patient'*. We built the coalition of the willing and the coalition of the ones who pull the strings in order to realize 'The Global Cancer Patient Bill of Rights'

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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 Bob Löwenberg (ErasmusMC)
- 18.45 - 19.15 The contribution of the WHO to patients globally Clement Chauvet (WHO/IARC)
- 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, Bob Löwenberg 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 - 08.45 Registration with coffee and tea
- 8.45 – 9.15 I'm a patient advocate by necessity Ligia Castro (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) &

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	the ones that need it most	Andrew Trister (Bill & Melinda Gates) (TBC)
10.15 – 10.45	I'm a scholar activist by necessity	Mark Lawler (Queens Univ. Belfast)
10.45 – 11.15	Coffee, tea and networking	
11.15 – 12.00	<u>Rapid fire talks of participants.</u> 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	<u>Out in the city.</u> In 3 groups we travel through Amsterdam and visit interesting organizations and places. <u>Group 1:</u> PharmAccess	Kwasi Boahene (PharmAccess) & Ilona Schelle
	<u>Group 2:</u> Tropenmuseum and Amsterdam tour	Gert Eijkelboom (DNB) & Nicole van Leeuwen (I2L)
	<u>Group 3:</u> HMF	Edwin Cuppen (HMF), Hans van Snellenberg (HMF) en 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. <i>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.</i>	
19.15 – 22.00	Dinner and music: Cello, performed by Fritz Schröder (ErasmusMC) and	

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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	Klaas Knot (DNB) (TBC)
9.30 – 10.00	I'm a patient advocate by necessity	Salomey Eferemor (I2L & PECA)
10.00 – 10.30	Moving Open Source Pharma to global patients	Mao Mao (I2L & Seekin)
10.30 – 11.00	Coffee, tea and networking	
11.00 – 12.30	Working sessions, lunch included. Participants choose group A, B, C or D.	
Participants work with leaders of the sessions and under the direction of PA's, towards the answer to the question: 'In the coalition of the willing, how do we unlock the Eminence in: science, care, industry and government?'		
<u>Group 1:</u> Finding & Funding. How to find money Rutger Stekelenburg (I2L) & For findings that benefit the global patient? Jaykumar Menon (OSP) (TBC)		
<u>Group 2:</u> Result from the Patient Advocacy meeting In September.		
<u>Group 3:</u> Result from the Patient Advocacy meeting In September.		
12.30 - 13.30	Panel discussion with funders for the findings	Panel lead: Jan Schuurman (I2L)
13.30 – 14.00	Report back from the working sessions	4 participants chosen in the sessions
14.00 – 14.15	What do I take home from the congress?	Participants chosen during the congress
14.15	End of conference – closing words	Ilona Schelle

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