



Inspire2Live World Campus vision

*"Sapere Aude" (dare to know)
I.Kant*

Inspire2Live convenes leading experts from a wide range of disciplines, we listen carefully to each scientist- leader; we integrate their perspectives and potential solutions and we educate not only the experts regarding the patient-perspective but also other patients together with care partners/providers, health systems, regulators, policy makers, payers and government officials, and the public at large.

Setting

On June 5 2020, Inspire2Live organized an online session to consult four leading scientists, namely Laura van 't Veer, Bob Weinberg, David Lane and Jan Hoeijmakers, about the global future of Inspire2Live which is committed to expanding its presence among patients and researchers all over the world. On June 26, the four science activists were asked to reflect on the first version of the report and comment on the planning of the global expansion so far.

This thoughtful and action-oriented exchange took place against the backdrop of the COVID-19 pandemic prompting the question about what we, as members of Inspire2Live, should do in this situation.

Cancer patients are a demographic that has been hit particularly hard by the coronavirus. The wounds that are inflicted vary markedly in severity when we also consider intersections with other factors, such as where you happen to be born, live and grow up, your gender, your dietary habits, whether you smoke or not, your work, the color of your skin, the country you live in, your postal code, your age, your environment and your genes.

Information about the nature of the virus, its impact and the human response was reaching us in bursts from Asia, Africa, Europe, North America, South America, Australia and New Zealand and the global perspective was practically forced upon us.

Concurrent with confronting the impact of the coronavirus on oncology patients, we must adapt Inspire2Live's efforts to improve the availability and effectiveness of cancer therapies in competition with COVID-19-only patients who, by the nature of the pandemic, have impacted and stressed national healthcare systems to the extreme. In this environment, Inspire2Live must also strive to ensure that oncology patients can continue to have access to the lifesaving care they require.

This is Inspire2Live's first step towards purposeful action on a global scale and, to do this, we seek the strengthening of **reciprocal** relationships with scholar activists and patient advocates from all continents.

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Introduction

Alluding to Bob Weinberg's dramatic outlook in 2011 at our first Annual Congress in Amsterdam, in 2020 cancer 'hit an iceberg' called corona. Not in a few unfortunate countries, not on one single continent, but all over the world.

Inspire2Live wants to create many hubs all over the world that share our wish to make this world a better place.

Prominent achievements of Inspire2Live

Since 2010, Inspire2Live has grown into a stable, warm, focused organization. In retrospect we can discern at least four ways in which the patient advocacy group has made its mark:

- 1. Community development:** Inspire2Live has become the action-center for an international group of dedicated patient advocates, medical researchers, doctors, scientists, politicians, entrepreneurs and government and bank officials. Each year a large fraction of the community meets at our annual congress in Amsterdam. The meetings are always a mix of science and patient experiences, emotion and reason, sadness about the loss of loved ones and vital energy, anger and remorse.
- 2. Science impact:** Inspire2Live has a keen eye for scientific research, state-of-the-art and on-the-edge treatments and new research techniques. The interest is often intensely personal with the desire to help one particular patient, but always with the next step in mind i.e.; what is necessary to get this personal treatment/care to all patients? Sometimes its impact goes much further. This was the case with the use of organoids for cancer research. Inspire2Live successfully pushed organoids onto the bench of many cancer research labs: Cold Spring Harbour Lab, MSKCC, Sanger, IGR to name just a few. The Dutch lead researcher Hans Clevers was challenged by Inspire2Live to share his ideas as a way of accelerating the transfer of his knowledge and competencies. A more recent example is fasting where Jan Hoeijmakers uncovered the biological mechanisms that fasting engenders leading to this being adopted by Laura van 't Veer as part of the UCSF breast cancer trials.
- 3. Political influence:** Inspire2Live has led several lobbying efforts. The Dutch parliament was successfully lobbied to vote for DNA sequencing as the norm for metastasized cancer patients. At EU level, Inspire2Live was invited to host a session on the pricing of drugs. On a global level, Inspire2Live is currently leading an international effort to bring a trial against the tobacco industry. And back in Europe, Inspire2Live brought the legal possibility of magisterial preparation to the awareness of the Dutch and European parliaments and the academic hospitals.
- 4. Institutional embedding:** Inspire2Live was created by cancer patients and attracted many more. It has always included the participation of scientists and

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doctors and is concerned with all types of cancer. Inspire2Live has had the good fortune to be supported by the Central Bank of the Netherlands, the Dutch Royal Academy of Arts and Sciences, by health insurance companies, entrepreneurs and many individuals. This support was always reciprocal and enabled a vital governance structure to emerge. The Inspire2Live governance and membership structure is the backbone of an organization that is ready to expand.

We do not know in advance to what extent achievements similar to ours will be relevant to other people and places. We contend, however, that by seeking reciprocal relationships with people like us from a variety of cultural backgrounds, we can and will strengthen each other and it is our ambition to initiate a patient organization that can act at the level of national and international institutions and governments such as the EU, UN and WHO.

To paraphrase Thomas Friedman in a recent op-ed in the New York Times: “Out of many, [acting as] we.”

Consultation of the leading scientists

The aim of Inspire2Live is to derive information from the consultation pertinent to what it wants to do. The summary therefore focuses on action sentences. Daring to know means daring to act which also means daring to focus.

Bob Weinberg addresses Inspire2Live by speaking to us directly, as “you”. He wants us to be cautious. Do things step-by-step and not take too big steps at once. He wants us to think of the profile of people and organizations that we would want to hook up with. We should ask ourselves what we think “they” can learn from us and what we can learn from “them”.

David Lane responds to Bob. He does not suggest caution but makes us aware of some critical differences between people and places. A good example he mentions is the financing of healthcare. Europe, the US and many Asian countries have completely different ways of financing healthcare. He believes we should focus on that which other organizations such as CRUK or NIH have not done or, due to their focus on funding, have failed to do. He wants us to talk to CRUK officials. What would they wish to do that has been neglected? David also encourages us to speak to people from his lab. Inspire2Live might be able to create the infrastructure for (inter)national cooperation and set up networks that may have political influence locally and globally.

Laura Van 't Veer suggests that we should listen to Sue Desmond-Hellman, the former CEO of the Bill and Melinda Gates Foundation, who said: “We failed on races and cultures.” In one word: focus on **equitability**. That is a strong imperative. We need to pick up on inequality. COVID-19 is hitting people of color with extra force. Add to the prevalence of cancer the disastrous inequality and the impact of a pandemic on top. Laura does not leave it there and sees an opportunity for the hubs in this respect: focus on the right **organization levels**: EU, UN(ESCO), WHO.

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Being the last in the series of consultations, Jan Hoeijmakers summarizes the points made by Bob, David and Laura. He stresses that **Inspire2Live can do things that “we, the scientists, cannot do”**. Work with people and organizations with the right mindset and skills. Create strong voices. Find your strength there and explore it with the hubs you help to create. He is a promoter of the idea to let scholar activists and patient advocates work together. By way of example, he reports his own research on **fasting**. Fasting is a relatively simple intervention but has huge impact on the benefit and harm done by many cancer treatments, in particular chemotherapy. The effect of fasting is now well understood and the biological mechanism of impact on treatment is universal. Hubs could benefit the spread of this kind of knowledge.

Discussion

We heard words of caution and encouragement. We are aware that the encounters with new people will broaden our outlook but they will also oblige us to seek focus. We want to be open to new venues, to learn and to further our focus whilst broadening and enriching our community, searching for good science and practices, educating and confronting politicians and influencing decision making.

We see two levels of exchange and impact.

1. We want to meet our equals and just sit down with them to discuss what we share, what makes us different and binds us together, what our experiences are. This should be a blend of informal exchange and structured meetings with patient advocates, doctors and scientists. The annual congress is a perfect spot to convene and organize demand-driven lectures for example. Over time, videoconferencing is a valuable way to further and deepen collaboration. It will be crucial to strive for reciprocity. Reciprocity is the building block of the cooperation between hubs, between members and which drives the interaction with others.
2. We hope to create a powerful action-center that is capable and respected. We do not mean “center” as one location, but as the combined strength of a crowd or **swarm**: ‘We are the center!’ As a network of hubs, we should be willing and able to organize outreach to both individuals in need of support and institutions at the level of the European Union, the United Nations (UNESCO in particular because of our focus on education) and the World Health Organization.

Conclusion

Inspire2Live is a warm organization. We do not wish to be driven by extremes of cold reason or hot emotion; we are as much driven by emotion as by reason. Sure, there is tension between the two, but there should be no opposition.

The metaphor we have chosen to illustrate this point is that we serve cappuccino, which is a blend of milk and coffee but is neither milk, nor coffee. Likewise, we will always aim at a delicate mélange of emotion and reason. Neither too hot nor too cold, but always warm.

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Continuous steps

1. Meetings with Bob, David, Laura and Jan may be called for and other scholar activists will be approached depending on the subject matter.
2. We will organize a team that will meet on a regular basis and this team will be extended over time. The team will be split up in hubs in Asia, the Americas, Africa, the Middle East and Australia. The team will figure out practices to reach out, enhancing the exchange of experiences and sharing successes and failures.
3. The Annual Congresses at the Royal Academy in Amsterdam will be the occasion to meet in a fully open environment. We will meet in person and, of course, this is a gathering of patients, scientists, doctors and others where we will serve cappuccino!

It is important to stress that we see the workshops as a cementing of the reciprocal relationships between people around the world. If required, we will organize lectures, invite experts and kick start critical developments.

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