



Strategic Policy Plan 2024

Executive Summary

Inspire2Live is a patient advocacy organization. The goal of Inspire2Live is to get cancer under control. We are convinced that this is achievable if patients, doctors, scientists, industry, regulators and funders work together to share knowledge, data and inspiration with each other. Then this doesn't have to take 50 years. Three core problems are:

- Currently, there is competition between faculties, research groups and universities. Moreover, there is a lot of work at cross purposes and the knowledge gained is not disseminated. Inspire2Live breaks through the stagnation by bringing together the various parties and well-informed patients and allowing them to work on concrete innovations.
- Much of the knowledge that is produced remains stuck in the academic stage or in ancient protocol conceptions and therefore does not reach broad medical practice. Moreover, the implementation power and willingness to change of the organizational structures is limited. As a result, essential innovations such as Personalized Medicine are stagnating. As a result, prevention does not receive the attention it deserves. In this context, efforts are being made to optimize the processes so that new ideas, therapies and treatments become available to patients worldwide more quickly.
- Thirdly, we do not see a problem, but rather an important opportunity in maximizing the use of similarly minded patients, doctors and scientists from the rich diversity of cultures and local approaches in other countries, including the Low- and Middle-Income Countries. This diversity brings benefits from a broader scope of experiences and approaches, but also from the widely different manifestations of cancer in different countries, the lack of a crippling advantage in poorer countries, which reduces institutional obstacles, and a leap forward can be made in one go. To this end, we have organized a Word Campus, which has already taken on a remarkable size and intensity in its first year and which has also brought several successful leaps forward in a number of countries. More than 90 lawyers from more than 40 countries are now affiliated with Inspire2Live.

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Introduction

Inducement

Inspire2Live originates from the fundraising organization Alpe d'HuZes. With the establishment of Inspire2Live in 2010, the founders of Alpe d'HuZes have made the logical next step from raising money to optimising how it is spent. Worldwide, more than €200 billion is spent annually on cancer research and the development of new medicines, while the return on that astronomical amount has been shockingly low for years. Inspire2Live puts the 'global patient' first and also assumes that real change will only come from the initiative of the patient.

Method used

Inspire2Live brings together all stakeholders from the medical industrial complex to search together for the optimal working method to optimally serve the interests of the patient. Depending on the subject, the financiers, industry and the government are also involved. Since 2019, we have been working on broad international cooperation in the spirit of Inspire2Live, which led to the establishment of the highly successful World Campus in 2020.

Data subjects

At the heart of the organization is a growing group of more than 90 patient advocates. Inspire2Live Patient Advocates are educated, articulate and well-informed patients or loved ones of patients who want to selflessly and independently dedicate themselves to others who are confronted with cancer. In addition to the Patient Advocates, there are the Scholar Activists, internationally renowned scientists who make their knowledge and brainpower available to the Inspire2Live projects. Together they form the World Campus.

Organization

Organization description

Inspire2Live is a foundation in the Netherlands that is formed by active patient advocates and scholar activists. These are selflessly committed to ensuring that patients have access to the best diagnoses and treatments now and in the future. Worldwide, the World Campus is a network of local advocates and scholar activists, which is now also affiliated with the World Health Organization.

Primary process and supporting processes

The primary process of Inspire2Live is to identify themes that are important to cancer patients. These can be new forms of diagnostics, new treatment methods, innovative therapies, more efficient business operations in healthcare, access to (new) medicines or access to clinical trials. We then organize working conferences where all stakeholders from the medical industrial complex work together on concrete action plans to make these things available to all patients in the world.

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Our primary goal is not to fund scientific research. However, sometimes it may be necessary to prove new concepts. This concerns proof of concept or validation research. In those cases, Inspire2Live is looking for funds to make this possible. In a number of cases, this has already led to concrete medical trials, medical information websites and initiatives are being taken to set up solid medical service organisations.

In summary, Inspire2Live is continuously networking, connecting, initiating. Inspire2Live does not (yet) employ or hire any staff and therefore has very little execution power. To solve this, Inspire2Live has had a subsidiary since 2022, called Saninfo, which is allowed to undertake commercial activities and can therefore achieve business results, invest and hire staff. Saninfo may also take on work assignments and carry them out under the supervision of Inspire2Live. This will be the case, for example, with Multi Cancer Early Detection (via SanInfo's subsidiary: OncoInv), DEEP diagnostics (see 6) and possibly also a new initiative on pain management for cancer patients.

Vision and mission

Vision: Inspire2Live believes that you will experience the greatest possible fulfillment if you put your heart and soul into the 'global patient'.

We work along three pillars:

- Make sure you don't get cancer (prevention)
- If you get cancer, make sure you detect it as soon as possible (early detection) and
- If you don't heal, make sure your quality of life is optimal for the time you have left (palliative care).

Onze missie: *'We're the patient's voice in cancer'. We're on a mission to inspire and empower all stakeholders from the medical industrial complex to work together to prevent, treat and eliminate cancer.'*

Organizational culture

Inspire2Live has a strong no-nonsense culture. We believe in positive activism to enable the right to the best treatments. We have great respect for the AIDS activists of the 1980s and 1990s, who demonstrated that much can be achieved when patients demand the right to innovative treatments.

Organisational structure

Inspire2Live is a foundation with a Supervisory Board, a board formed by three directors. In addition to this management, Inspire2Live has a management team in which the functions; Communication, Finance, Office Management and Program Management are represented. The board will be formed in 2024 by Ilona Schelle, Peter Kapitein and Tielo Jongmans.

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Critical Success Factors

Independence. We must ensure at all times that we do not become dependent on any party. Only if we can always fully focus on the interests of the 'global patient' can we make a difference.

Dare to dream. For a cancer patient, hope is life. We dare to put a dot on the horizon and go for it with full strength and commitment. As unrealistic as it may sound at first, we aim to make the impossible happen.

Selflessness. We are guided by the intrinsic desire to improve the quality of life of others and not to satisfy our own ego.

Give up. The willingness to personally renounce in order to achieve the higher goal is crucial to the success of the mission.

Passion. Passion is what connects us. The will to live and to support others who have to deal with cancer as much as possible in their struggle, gives the satisfaction we do it for.

Current situation

Inspire2live will acquire its funds from a variety of sources.

- Inspire2Live has a network of corporate sponsors who can be approached on an ad-hoc basis for sponsoring (theme) conferences.
- Inspire2Live has started approaching sponsors and donors on the basis of a document that describes what happens when you support Inspire2Live.
- For the Annual Congress, we are sponsored by the industry with the guarantee of our independence. We will never offer exclusivity to a financier.

Cost of target spend vs. overhead

In 2024, the majority of the budget will be spent on target spending. Small sums are spent on, for example, travel expenses to those who cannot afford to pay for it themselves. The transportation to and stay during the Annual Congress of our patient advocates and scholar activists is reimbursed from the funds made available for the Annual Congress.

Given the limited financial resources, the other overhead tasks will be carried out on a voluntary basis.

By target spending we mean the following costs:

- Organizing conferences
- Setting up and facilitating Discovery Networks
- Further expansion of the World Campus

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- Possibly financing proof of concept studies if no external funding can be found for this.
- External communication
- Developing affiliate business structures for actual services or products (e.g. SanInfo)
- Management program

Overhead includes the following costs:

- Accounting
- Leading the organization (<10% time spent on the board)
- Office management
- Fundraising

Organization

Strong

- Highly motivated Patient Advocates who link knowledge, experience and sense of urgency to concrete actions.
- Very large network within the medical world, both nationally and internationally.
- Conceptually powerful because many Patient Advocates and Scholar Activists are of a high scientific or societal level
- Not bound by institutional frameworks or historical roles.
- Greatly increased number of Advocates throughout the World Campus.
- Prestige among top experts.
- Considerably increased awareness among politicians in Brussels, making high-quality lobbying possible.
- Strong Vision, Great Out-of-the-Box Capability

Weak

- Leaning on volunteers, which means that sometimes things are left longer than desired.
- Dependency on corporate goodwill sponsors for financing projects
- Approach to labour-intensive projects is limited due to limits, capacity and employability of PAs (Most PAs need income and are therefore tied to a job)
- In many situations, the independence of Inspire2Live clashes with institutional self-interest or established practices of the medical-industrial complex and can therefore arouse suspicion

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Staff/Volunteers

Strong

- Very driven
- Hands-on expert
- Highly educated
- Eloquent
- Bold
- Visionair
- Critical

Weak

- Some plans require very long breath and multiple attempts
- Capacity
- Vulnerable to opposition

Commercial

Strong

- Good international network with other charities

Weak

- Little experience in fundraising
- Dependency on goodwill.

Finance

Strong

- Reliable sponsoring Annual Congress

Weak

- Uncertainty of success in the search for sponsors

Chances

- In the world of cancer research and treatment, Inspire2Live has a good name that is becoming more and more known, which means that we are increasingly asked to think and work with you
- A lot of attention in the media about innovative ways to optimize diagnosis and treatment of patients (think of OncoSeek)
- Public debate on the costs of healthcare in relation to an ageing population and an increase in the incidence of cancer

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- The patient's voice is not yet taken seriously enough, but that voice is becoming increasingly powerful.
- The first political successes have been achieved.
- With limited interventions, a lot can be achieved in a healthcare landscape that is stuck.
- Under pressure from the cuts in research budgets, researchers and universities are increasingly working together.

Threats

- Conservative medical profession is not open to real innovation
- Changes in healthcare are very slow
- Cancer patients are often elderly and weakened, and therefore often not very activist, due to their nature or limitations.
- In many countries, cancer is not yet a problem because it is concealed (individually) or has to be concealed (because it is a stigma or is perceived as witchcraft)
- Powerful and alert lobby from the pharmaceutical and tobacco industries.
- Counterproductive financial incentives for physicians and institutions

Policy and strategy

Organizational Goals

The goal of Inspire2Live is to get cancer under control and ensure that everyone has access to the best cancer care. So, on the one hand, to ensure that new effective therapies are developed to control cancer and, on the other hand, to ensure that these therapies are also available to everyone; for the 'global patient.'

Strategies

Inspire2Live brings patients, scientists and doctors together worldwide (the best of the best) with the aim of initiating collaboration in the field of innovation and implementation. Inspire2Live initiates collaborations between the world's top institutes in the field of cancer research to join forces in the field of new innovations. In case of proven success, we establish contacts between these partnerships and renowned funds such as the Dutch Cancer Society, National Cancer Institute, Cancer Research UK, World Health Organization, etc., to further support these successes.

Description of the desired situation

The most optimal situation is if cancer patients, following the example of the advocates of Inspire2Live and international sister organizations, stand up for their right to the best treatment. The activism of the AIDS movement in the 1980s and 1990s has shown that patients can have a very powerful voice in enforcing far-reaching measures in both industry and government. The World Campus is the vehicle for this.

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Projects and measures

- Annual Conference 2024 Inspire2Live
- Facilitating World Campus
- Organizing Discovery Networks
- The guide for the 'global patient' via Saninfo
- Adjusting the research calendar to a calendar that focuses more on the patient and is more flexible in terms of research and implementation methodology. Among other things, through the membership of IHI (EU initiative).
- Multi Cancer Early Detection via SanInfo/Oncolnv
- DEEP Diagnostics, intended to develop and realize Precision Medicine in the most advanced form.

Risks

-loss of financial sources

-Loss of key figures

-negative publicity

Budget

Expenditure target spending 2024

Organizing theme conferences (1)	€10,000.00
World Campus	€10,000.00
Travel and accommodation costs abroad	€20,000.00
DEEP Diagnostics	Pm
Annual Congress	€ 135.000,00
Total	€175,000.00

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Expenses overhead 2024

In 2024, less than € 1,000.00 will be spent on the remuneration for the office manager and the webmaster.

Revenue 2024

Sponsorship by two IT companies	€30,000.00
Sponsorship industry	€ 100.000,00
Fundraising events	€45,000.00
Total	€175,000.00

Other financial:

Both the Supervisory Board and the directors are unpaid and only declare the expenses incurred by them in accordance with the policy established by Inspire2Live in the I2L Code of Conduct (<https://inspire2live.org/wp-content/uploads/2019/07/Inspire2Live-Code-of-Conduct-I2L.pdf>). The costs are therefore virtually nil.

If additional budget becomes available in the future, part of that budget will be used to deploy paid staff who will be involved in the organization of the activities that are essential to ensure the continuity of the organization. In 2024, all tasks will be carried out on a voluntary basis.

Payment of the directors is determined by the Supervisory Board, payment of other positions is determined by the board. No payment will be made for 2024 due to limited financial resources. If more financial resources are available, the board will decide whether people within the organization can be paid.

Peter Kapitein's work and expenses for Inspire2Live are paid for by the Dutch Central Bank and are therefore not at the expense of Inspire2Live.

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