

# Strategic Policy Plan 2022

### Management summary

Inspire2Live is a patient advocacy organisation with the goal of bringing cancer under control. We are convinced that this is possible if patients, doctors and scientists collaborate globally - sharing knowledge, data and inspiration. If that is the case then it does not have to take 50 years. There are two main obstacles:

Currently there is an unhealthy competition between faculties, research groups and universities. Also, a lot of work is done in isolation and knowledge gained often gets no further distribution. Inspire2Live breaks through this stagnation by bringing these parties together and connecting them with well-informed patients to work together to bring about concrete innovations.

Much knowledge that is produced gets no further than Academy, or remains stuck in antiquated protocol-settings and therefore doesn't reach broad medical application. Next there are the inadequate willingness to change and power to implement within the medical mega-structures. This causes essential innovations like Personalised Medicine to stagnate. Prevention is another major victim of lack of attention.

This is the context in which we work to optimise processes to make new ideas, therapies and treatments available sooner to patients in the Netherlands, and worldwide.

What we consider to be not a problem but a great opportunity is to get as much involvement as possible from like-minded patients, doctors and scientists from the rich diversity of cultures and local approaches in other countries, including the third world. This diversity brings the broader scope of experiences and circumstances, but also the very different distributions and properties of cancer in different countries. In poorer countries there is no diminishing return, less institutional and systemic obstacles so that greater leaps forward are possible.

This has led us to take the initiative towards a Worls Campus, which already in its first year has reached a significant number of participating countries and people, who work with great intensity and who together have already brought many significant progresses to a number of countries.

### Introduction

1.1 Rationale

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Inspire2Live is an initiative founded by the fund-raising organisation Alpe d'HuZes. With the establishment of Inspire2Live in 2010, the founders of Alpe d'HuZes made the logical next step from raising funds to optimising the way these funds are spent. Annually, more than € 200 billion is spent on cancer research and the development of new cancer drugs worldwide. However, the yield of this astronomical amount has been shockingly low for many years. Inspire2Live focuses on the patient and expects the patient to take the initiative to initiate real change.

#### 1.2 Methodology

Inspire2Live connects cancer patients, doctors and scientists to find the optimal approach to serve the best interests of the patient. Depending on the topic, we also involve health insurers, industry or the government. Since 2019 we have been intensifying international cooperation in the same spirit, which has led in 2020 to the launch of the very successful World Campus.

#### 1.3 Stakeholders

At the heart of the organisation is a group of approximately 75 patient advocates. Patient advocates of Inspire2Live are highly educated, articulate, well-informed patients or their loved ones, who are selflessly and independently committed to helping others with cancer. Next to the Patient Advocates there are the Scholar Activists, scientists of world renown who make their knowledge and thinking powers available to the projects of Inspire2Live.

### 2 Organisation

#### 2.1 Organisational overview

Inspire2Live is a foundation formed by very active (former) cancer patients and their loved ones. These patient advocates are selflessly committed to ensuring that patients have access to the best treatments - now and in the future. Worldwide this branches out into the World Campus, a network of local Patient Advocates and Scholar Activists, which has recently become allied to the World Health Association.

#### 2.2 Primary and ancillary processes

The primary process of Inspire2Live is to identify topics that are important to cancer patients, such as new treatments, innovative therapies, more efficient healthcare management and access to new drugs and clinical studies. We subsequently organise working conferences where leading physicians, scientists and, if appropriate, representatives of government, industry and health insurers, work with patient advocates on concrete action plans to make these resources available to all patients.

Funding scientific research is not our primary goal. However, it may sometimes be necessary to prove new concepts - this is known as Proof-of-Concept research. In these



cases, Inspire2Live seeks funding to make it possible. This has already led to concrete medical trials, informative websites, and to initiatives with the aim to set up sound medical service-organisations.

In summary, Inspire2Live is continuously working on networking, connecting, initiating. Inspire2Live does not employ or hire staff and therefore has very little execution power. To solve this problem, Inspire2Live has had a subsidiary called Saninfo since 2022, which is allowed to undertake commercial activities, and which can therefore book business results, invest, and hire staff. Saninfo can also take work orders and carry them out under the supervision of Inspire2Live. This will be the case, for example, with DEEP diagnostics (see 6).

#### 2.3 Vision and mission

Vision: Inspire2Live believes that the greatest fulfilment comes from devoting yourself heart and soul to helping others.

Mission: To bring cancer under control, thereby enabling patients to live a good, happy and healthy life in spite of cancer.

2.4 Organisational culture

Inspire2Live has a strong no-nonsense culture. We believe in positive activism, enabling cancer patients to exercise their right to receiving the best treatment. We have great respect for the aids-activists from the 1980s and 1990s who have shown how much can be achieved if patients demand their right to innovative treatments.

2.5 Organisational structure

Inspire2Live is a foundation with a Supervisory Board and an Executive Board. The Executive Board consists of two members, including the Chairman. In addition, Inspire2Live has a Management Team that is responsible for communication, finance, office management and program management. In 2022, Tielo Jongmans will take on the role of Chairman, and the Executive Board will consist of Tielo Jongmans and Peter Kapitein.

#### 2.6 Critical success factors

Independence. We must always ensure that we do not become dependent on another party. It is only when we are fully focused on the needs of the patient that we are really able to make a difference.

The courage to dream. For a cancer patient, hope is life. We have the courage to set ambitious goals, and we strive to reach these goals with all our energy and commitment. No matter how unrealistic it may seem at first, we aim to make the impossible possible.

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

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No shirking from disappointment or discomfort. A preparedness to risk disappointment or discomfort in the interests of achieving a higher goal is crucial to the success of our mission.

Passion. We are united by our passion. Our satisfaction is provided by the will to live and fully supporting others in their fight against cancer.

### 3 Current situation

#### Inspire2Live will raise funds from various sources.

- Inspire2Live has a network of corporate sponsors that can be approached on an ad hoc basis to sponsor (theme based) conferences.
- Inspire2Live has started approaching sponsors and donors, based on a document describing what to expect when supporting Inspire2Live.

#### Targeted expenditure vs overhead expenses

In 2022, the majority of the budget will be allocated to targeted expenditure. The Office Manager and the Webmaster will each receive  $\leq$  5,000.00 gross per year. The organiser of the World Campus  $\leq$  5.000 as well.

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

#### Targeted expenditure includes the following

- Organising conferences
- Establishing and facilitating discovery networks
- Further expansion of the World Campus
- Possible funding for proof or concept research if it cannot be funded externally
- External communication
- Developing allied company-set-ups for operational services or products
- (SanInfo)
- Program management

#### Overhead expenses include the following

- Accounting
- Management of organisation (<10% time spent by management)
- Office management
- Fund-raising

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### 4 Analysis of current situation

4.1 Internal analysis

#### Organisation

#### <u>Strengths</u>

- Highly driven patient advocates who are able to link knowledge, experience and a sense of urgency to concrete actions
- Extensive network within the medical world, both nationally and internationally
- Conceptually strong because of independence from historical frameworks or roles.
- Prestige from top experts
- Much improved presence in national and European politics, therefore more lobbyimpact
- Strong vision, out-of-the-box capability

#### <u>Weaknesses</u>

- Heavily reliant on volunteers, resulting in delays in the completion of tasks
- Dependent on the goodwill of corporate sponsors for financing projects
- Possibilities for taking on labour-intensive projects are limited, due to the limits in capacity to employ PAs (PAs are usually in paid employment elsewhere because they require an income)

#### Staff / volunteers

#### <u>Strengths</u>

- Highly driven
- Expert by experience
- Highly educated
- Articulate
- Thorough and purposeful
- Visionary
- Analytical

#### <u>Weaknesses</u>

- Some plans take a long time and sometimes require multiple attempts
- Capacity

#### Commercial

<u>Strengths</u>

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- Good international charity network
- Experienced in fund-raising (e.g. Alpe d'HuZes)

#### <u>Weaknesses</u>

- Dependency on goodwill and 'click' sponsors

#### Financial

#### Strengths

- Cash position for activities in 2022, for the first time there is some room for quality support
- Reliable sponsoring for the Annual Congress

#### Weaknesses

- Uncertainty of success in finding sponsors
- 4.2 External analysis

#### Opportunities

- In the world of cancer research and treatment, Inspire2Live has built a good reputation which is becoming more well-known. Therefore, we are increasingly invited to provide input for and cooperate with other organisations.
- Innovative approaches to optimise treatment for cancer patients are receiving considerable attention in the media.
- Public debate about the costs of healthcare in connection with an ageing population and an increase in the incidence of cancer.
- While the voice of the patient is currently still not taken seriously enough, it is increasingly becoming stronger.
- First political successes have been achieved.
- With limited intervention, a lot can be achieved in a healthcare landscape that is gridlocked.
- Researchers and universities are increasingly cooperating under pressure from budget cuts in research.

#### <u>Risks</u>

- Conservative medical world is not open to real innovation
- Changes in healthcare generally progress very slowly
- Cancer patients are often elderly and usually not activists by nature (or because of their physical limitations)
- Powerful lobbying from the pharmaceutical and tobacco industries
- Counterproductive or even perverse financial incentives for physicians and institutions

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### 5 Policy and strategy

#### 5.1 Organisational goals

The goal of Inspire2Live is to get cancer under control and ensure that every patient has access to the best cancer care. Therefore, we want to ensure that new effective cancer therapies are developed, while at the same time ensuring that these therapies are available to all patients.

#### 5.2 Strategy

Inspire2Live brings together cancer patients, scientists and doctors from all over the world (the best of the best) and initiates cooperation in the field of innovation and implementation. Inspire2Live encourages the world's top cancer research institutes to join forces in the field of new innovations. When successful, we establish contact between these partnerships and renowned funds such as the KWF, National Cancer Institute and Cancer Research UK, WHO etc for further support.

#### 5.3 Desired situation

The optimal situation is when cancer patients, following the example of patient advocates from Inspire2Live and international sister organisations in the US, 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 demanding far-reaching measures in both industry and government. The World Campus is the vehicle for this.

### 6 Projects and activities

Inspire2Live will have the following projects and activities in 2022:

- Inspire2live annual conference 2022
- World Congress World Campus
- Theme based conference 'Lifestyle and cancer'
- Establishing discovery networks (Al and Cancer)
- Excellent cancer centres via Inspire2Go
- Adjusting the research calendar to be more patient focused and flexible in terms of research and implementation methodology
- DEEP Diagnostics, the most ambitious undertaking of Inspire2Live ever, to develop and implement Precision Medicine in its most advanced form.

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### 7 Budget

Targeted expenditure 2022

| Organizing theme congresses (1) | € 10.000,00    |
|---------------------------------|----------------|
| World Campus Congress           | € 30.000,00    |
| Travelling and housing          | € 20.000,00    |
| Start DEEP Diagnostics          | € 3.000.000,00 |
| Total                           | € 3.060.000    |

#### Overhead expenses 2022

In 2022,  $\in$  15,000, 00 will be spent on compensation for the Office Manager, the Webmaster and the organiser of the World Campus.

#### Income 2022

| Sponsorship two IT-companies         | € 50.000,00    |
|--------------------------------------|----------------|
| Sponsorship other organizations      | € 35.000,00    |
| Fundraising events                   | € 15.000,00    |
| Additional fundraising (among others | €              |
| EU4Health voor DEEP Diagnostics)     | 2.900.000,00   |
| Total                                | € 3.000.000,00 |

#### Other income and expenditure

Both the Supervisory Board and the Chairman positions are unpaid. In line with the policy adopted by Inspire2Live in the Code of Conduct I2L, they only declare the relevant expenses. Administrative costs are therefore virtually nil.

If additional capital should become available in future, part of that capital will be used to recruit paid employees to organise activities that are essential to the continuity of the organisation. However, in 2022, all other tasks will be carried out on a voluntary basis.

The Supervisory Board will determine the remuneration of the members of the Executive Board. The Executive Board will determine remuneration for all other functions. However, due to limited financial resources, no remuneration will be made for 2022. If more

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financial resources become available, the Executive Board will decide whether staff within the organisation will be remunerated.

The Dutch National Bank sponsors the work and expenses of Peter Kapitein and these are therefore not charged at the expense of Inspire2Live.

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