



## Strategic Policy Plan 2020

### 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. This collaboration will also make the process much quicker. Unfortunately, there is currently an unhealthy competition between faculties, research groups and universities. However, Inspire2Live brings these parties together, connecting them with well-informed patients. These stakeholders can therefore work together to optimise the processes so that new ideas, therapies and treatments become available much faster, not only to patients in the Netherlands, but also worldwide.

## 1 Introduction

### 1.1 Rationale

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.

### 1.3 Stakeholders

At the heart of the organisation is a group of approximately 45 patient advocates. Patient advocates of Inspire2Live are well-educated, articulate, informed patients or their loved ones, who are selflessly and independently committed to helping others with cancer.

## 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.

### 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 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.

### 2.3 Vision and mission

Vision: Inspire2Live believes that the greatest satisfaction comes from devoting yourself to helping others.

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

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## 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 the 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 2020, 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.

**Relinquishing personal gain.** A willingness to relinquish personal gain 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.
- The Dutch Cancer Society (KWF) has donated € 30.000 for the Inspire2Live 2020 annual conference.

## **Targeted expenditure vs overhead expenses**

In 2020, the majority of the budget will be allocated to targeted expenditure. The Office Manager and the Webmaster will each receive € 5,000.00 gross per year.

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
- Establishing (inter)national collaborations between cancer patients, scientists and doctors
- Possible funding for proof or concept research if it cannot be funded externally
- External communication
- Program management

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**Overhead expenses include the following**

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

## **4 Analysis of current situation**

### 4.1 Internal analysis

#### **Organisation**

##### Strengths

- 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
- Prestige from top experts
- Strong vision

##### Weaknesses

- 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 because they require an income)

#### **Staff / volunteers**

##### Strengths

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

##### Weaknesses

- Some ideas take a very long time to come to fruition and require multiple attempts
- Capacity

#### **Commercial**

##### Strengths

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

##### Weaknesses

- Dependency on goodwill and 'click' sponsors

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## Financial

### Strengths

- Cash position for activities in 2020
- Prospect of cash flow 2020 and beyond

### 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.
- 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.

### Risks

- 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
- Powerful lobbying from the pharmaceutical and tobacco industries
- Counterproductive financial incentives for physicians and institutions

## 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 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. To achieve this, we are now working actively in setting up Inspire2Live hubs in Singapore, Boston, San Francisco, Latin America and Africa.

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## 6 Projects and activities

Inspire2Live will have the following projects and activities in 2020:

- Inspire2live annual conference 2020
- Theme based conference 'Operating without cutting'
- Theme based conference 'Lifestyle for prevention and cure'
- Establishing discovery networks (Vaccines and Cancer, Children and Cancer, AI and Cancer)
- Excellent cancer centres via Inspire2Go
- Access to medicine through our partner organisation DCLA
- Adjusting the research calendar to be more patient focused and flexible in terms of research and implementation methodology

## 7 Budget

### Targeted expenditure 2020

- Organising theme based conferences (3)	€ 15.000,00
- Annual conference	€ 40.000,00
- Miscellaneous project financing	€ 10.000,00
- International travel and accommodation	€ 20.000,00

### Overhead expenses 2020

In 2020, € 10,000, 00 will be spent on compensation for the Office Manager and the Webmaster, as well as € 5,000,00 for domestic travel and compensation for meals.

### Income 2020

- Sponsorship for annual conference from two IT companies	€ 50.000,00
- Sponsorship from other organisations	€ 30.000,00
- Fund-raising events	€ 15.000,00

### 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 2020, all 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 2020. If more 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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