



Strategic policy plan 2019

Management summary

Inspire2Live is a patient advocacy organisation whose aim is to get cancer under control. We are firmly convinced that this is achievable provided that patients, doctors and researchers worldwide all work together to share knowledge, data and inspiration. Unfortunately, faculties, research groups and universities are currently engaged in unhealthy competition. Inspire2Live brings these various players together with groups of highly informed patients. All these stakeholders are then encouraged to work on optimising the processes involved so that new ideas, therapies and treatments are made available much faster to patients, not just in the Netherlands but all over the world.

1 Introduction

1.1 Rationale

Inspire2Live is an initiative devised by the fund-raising organisation Alpe d'HuZes. With the establishment of Inspire2Live in 2010, the founders of Alpe d'HuZes took the logical next step from raising funds to optimising the way they are spent. Each year, over €200 billion is spent on cancer research and on the development of new cancer drugs worldwide. The return on this astronomical sum has been shockingly low for many years. Inspire2Live puts patients centre stage and also expects them to take the initiative in order to bring about real change.

1.2 The approach

Inspire2Live brings together patients, doctors and researchers to jointly find the best approach to serve interests of patients. Depending on the topic, we will invite Health Care Insurers, Government or Industry to join.

1.3 Stakeholders

At the heart of the organisation is a group of approximately 35 patient advocates. The Inspire2Live patient advocates are educated, eloquent and well-informed patients or their relatives, who are selflessly and independently committed to helping others cope with the disease.

2 Organisation

2.1 Description of the organisation

Inspire2Live is a foundation consisting of a number of highly active (former) cancer patients and relatives of patients. These patient advocates are committed to selflessly 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 important themes for cancer sufferers, such as new treatments, innovative therapies, more efficient ways to administer health care, access to new drugs or access to clinical studies. We then organise working conferences at which leading consultants and researchers, and sometimes representatives for government or industry to work with patient advocates on concrete action plans to make these facilities available to all patients.

Our primary goal is not to fund medical research, although it can sometimes be necessary to demonstrate that new concepts work. This is known as Proof of Concept research. Where necessary, Inspire2Live looks for funding to make this possible.

2.3 Vision and mission

Vision: Inspire2Live believes that the greatest possible satisfaction comes from putting your heart and soul into helping your fellow citizens.

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Mission: To bring cancer under control so that patients can live a happy and healthy life in harmony with cancer.

2.4 Organisational culture

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

2.5 Organisational structure

Inspire2Live is a charitable foundation with a Supervisory Board and an Executive Board consisting of a President and a Board of Directors. The President is also a member of the Board of Directors. There are two people on the Board of Directors. In addition to the Board of Directors, Inspire2Live also has a 4-strong management team who deal with communication, finance, office management and program management respectively. In 2019, the Board of Directors will consist of Peter Kapitein and Tielo Jongmans. Tielo Jongmans will additionally exercise the role of President.

2.6 Critical success factors

Independence. We must ensure that we never become dependent on any party. Only if we can always focus fully on the interests of cancer sufferers will we really be able to make the difference.

Daring to dream. For cancer patients, hope is life. We dare to set our sights on a goal and to strive towards it with all our energy and conviction. No matter how unrealistic it may at first seem, we are committed to making the impossible a reality.

Selflessness. We are motivated by an intrinsic desire to improve the quality of life for others and not to salve our own ego.

Relinquishing personal gain. A preparedness to relinquish personal gain in the interests of achieving a higher goal is crucial for the success of our mission.

Passion. We are united by a passion for what we are trying to achieve. The will to live and to give maximum support to others in their fight against cancer is what gives us the satisfaction we seek.

3 Current situation

Inspire2live will raise funds from various sources.

- Inspire2Live has a network of corporate sponsors who can be approached on an ad hoc basis to sponsor conferences (focusing on a specific theme).
- Inspire2Live has started approaching sponsors and donors on the basis of a document that describes what you may expect when you support Inspire2Live.
- We are working on a 'Friends of Inspire2Live' initiative for smaller and larger donations.

Costs of target spending versus overheads

In 2019, the whole of the budget will be allocated to target spending. In view of the limited capital available, overhead tasks will be carried out on a voluntary basis.

Target spending covers the following:

- Organising conferences
- Establishing and facilitating Discovery Networks

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- Organising (inter) national cooperation between patients, researchers and doctors
- Financing proof of concept studies if they cannot be externally funded
- Performing external communication actions
- Carrying on programme management

Overheads cover the costs of the following activities:

- Bookkeeping and accounting
- Managing the organisation (10% of the Board of Directors' time commitment)
- Performing office management tasks
- Fund-raising

4 Analysis of the current situation

4.1 Internal analysis

Organisation

Strengths:

- Highly driven patient advocates who link knowledge, experience and a sense of urgency to concrete actions.
- Extensive network in the medical world, both national and international.
- Strong vision.

Weaknesses:

- Heavily reliant on volunteers, as a result of which it sometimes takes longer to do things than is desirable.
- Dependency of corporate sponsors for financing projects.
- The possibilities for labour-intensive projects are limited due to capacity limits and employability of PAs (Most PAs need income and are therefore bound to a job).

Staff/Volunteers

Strengths:

- Highly driven
- Considerable practical experience
- Well-educated
- Vocal
- Decisive and resolute

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- Visionary
- Critical

Weaknesses:

- Reality content of plans
- Capacity

Commercial

Strengths:

- Good networking with international charities
- Experienced in fund-raising (e.g. Alpe d'HuZes)

Weaknesses:

- Dependency goodwill corporate sponsors

Finances

Strengths:

- Cash position for 2019 activities
- Prospect of steady income 2019 and beyond.

Weaknesses:

- Uncertainty success 'Vrienden van Inspire2Live' and other sources of funding.

4.2 External analysis

Opportunities:

- In the world of cancer research and treatment, Inspire2Live has a good name which is becoming progressively well-known, as a result of which we are increasingly asked to provide input for, and work with, other organisations
- Considerable media attention for our innovative approach to optimising patient treatment
- Public debate on the costs of care in combination with an ageing population and growing incidence of cancer
- Voice of the patient is still not taken seriously enough, but is becoming stronger
- Much can be achieved through limited intervention in a medical landscape which is gridlocked
- Researchers and universities are increasingly working together as research budgets are progressively squeezed

Threats:

- The conservative medical world is not open to radical innovations

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- Change within the healthcare field generally is slow.
- Cancer sufferers are usually elderly and not activist by nature
- Powerful counter-lobby from the pharmaceutical industry

5 Policy and strategy

5.1 Organisational goals

The goal of Inspire2Live is to get cancer under control and ensure that everyone has access to the best cancer care. In other words, to ensure that new effective therapies are developed to bring cancer in check and to ensure that these therapies are made available to everyone.

5.2 Strategy

Inspire2Live brings together patients, researchers and doctors worldwide (the 'best of the best') with the aim of encouraging them to work together to pursue innovation and implementation. Inspire2Live initiates cooperation between the global top institutes in the field of cancer research and encourages them to pool their strengths on behalf of new innovations. Where there is proven success, we will establish contacts between these partnerships and reputable funds such as the Dutch Cancer Society (KWF), the National Cancer Institute and Cancer Research UK, so that these successes can receive further support. The Discovery Network Targeted Medicine project, which we launched in 2011, is a good example; it is currently being strongly financed from both the Netherlands and the United States. A recent article in *Cell* (an authoritative cancer research journal) acknowledged that Inspire2Live was behind the project, and expressed its appreciation for the initiative.

5.3 The required situation

The optimum situation would be for cancer sufferers to stand up for their right to receive the best treatment, in emulation of the patient advocates of Inspire2Live and international sister organisations in the United States. The activism of the AIDS movement in the 1980s and 1990s showed that patients can acquire a very powerful voice in demanding far-reaching action from both industry and the government.

6 Projects and measures

- Annual Conference 2019
- Theme-based conference Diagnostics (to be planned)
- To be defined theme congress
- Setting up Discovery Networks (HIV and Cancer, Children and Sarcoma)
- Excellent cancer centres
- Access to medicines
- Adjusting the research calendar to a calendar that places the patient more central and that is more flexible in terms of research and implementation methodology

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7 Budget

Target spending in 2019

- Organising 3 theme-based conferences	€ 15.000
- Annual conference	€ 50.000
- Miscellaneous project financing	€ 10.000
- International travel and accommodation	€ 20.000

Overheads in 2019

There will be no overhead costs in 2019

Income in 2019

- Annual conference sponsorship by 2 IT companies	€ 55.000
- Extra corporate sponsorship	€ 40.000

Other income and expenditure:

Both the Supervisory Board and the CEO positions are unpaid; they only submit expenses, in line with the relevant policy outlined by Inspire2Live in the I2L Code of Conduct. Running costs are thus practically nil.

If additional capital should become available in the future, part of this budget will be used to recruit paid staff to organise activities that are essential to ensure the continuity of the organisation. In 2019, all tasks will be performed on a voluntary basis.

The Supervisory Board will determine the remuneration of the President and Board of Directors. The Board of Directors will determine all other payments. No remuneration will be paid for 2019 in view of the limited funds available. If additional capital becomes available, the Board of Directors will determine whether people can be paid within the organization.

The work of Peter Kapitein for Inspire2Live is paid by De Nederlandsche Bank and is therefore not at the expense of Inspire2Live.

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