

# Stichting Inspire2Live

## Financial Report 2016

Version: April 25<sup>th</sup>, 2016



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## Supervisory Board report

2016 has been the first full year of activity of the current supervisory board, which was instated in 2015. After a short period of getting to know each other and exploring effective ways of interacting with the board of directors of Inspire2Live (consisting of Erik van Veenendaal and Peter Kapitein), the periodical meetings of the supervisory board with the board of directors, were effective, productive and inspiring. This way the supervisory board contributed to the important work of Inspire2Live.

We strongly feel that we operate according to the Declaration of Intent drafted by the Supervisory Board and published in the Annual Report of 2015, in a natural and unforced manner.

In 2016 Sylvia Butzke joined the supervisory board. Her skills, knowledge and character add to the diversity of the Supervisory Board. Now we can even better look at the current and future vision, plans and actions of Inspire2Live from different angles and help the Board in any way we can, within the frame we operate.

Inspire2Live has accomplished a lot in 2016. An overview is given hereafter in the Board report.

The Supervisory Board concludes that no irregularities or unwanted behaviour have taken place in 2016 and we endorse this Annual Report.

The activities in 2017 have been launched successfully. For more details please consult our website.

Amsterdam, April 25<sup>th</sup>, 2017,

R. Stekelenburg, Chairman of the Supervisory Board

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## Board report

This Board report contains information about our financial year 2016. The new governance structure was implemented in 2015 and proved to work sufficiently in 2016. Inspire2Live has a governing board, which is formed by Erik van Veenendaal. A board of directors manages the daily operations. Peter Kapitein, CEO, is responsible for the operational processes and Erik van Veenendaal, Chief Visionary Officer, is responsible for developing new ideas for the future steps to be taken.

The Supervisory Board of Inspire2Live is expanded with one new board member: Sylvia Butzke.

In 2016 René Boutkan joined Inspire2Live as the successor of Daniël Kleijn. René is now the Financial Manager. We thank Daniël for his contribution and will never forget his enormous work during the 2013 crisis we faced.

Our organization now consists of 35 active patient advocates of which one in the USA, one in the UK, one in Sweden and one in Switzerland. Our patient advocates are highly educated, well informed and eloquent. They combine emotion (as a driving force) with information and knowledge. Our patient advocates are visible in dozens of initiatives, give dozens of talks and write dozens of blogs, articles and books.

Inspire2Live started the patient initiative 'That's my data. Use my data' in 2015 and has cooperated with Dutch organizations with lots of patient data in 2016 intensely. The working title is 'Mysmallstep.com'. We will set up a call for action towards patients to donate their medical data. This campaign will be launched in 2017.

### Congresses by Inspire2Live:

1. 'Annual Congress; 'Walk the extra mile for the patient'. We had a lot of positive reactions. Most people like the active interaction between the various stakeholders who all participate: patients, researchers, clinicians, government, industry and health insurance companies. This is new and very effective. Shortly after the congress we already had several activities taken place. For a summary and the talks one can take a look at the site.
2. We organized together with Cinderella Therapeutics a congress about 'Affordable drugs'. This led to a position paper for the Dutch with 4 suggestions for price reduction. Look at our website for the position paper.
3. 'Beyond Randomized Clinical Trials'. Gaston Remmers has organized a great conference with approximately 50 participants, great speakers and very creative break-out sessions. Very nice vibe and lots of ideas on how patients can be involved in more effective ways to achieve scientific progress.
4. Gaston Remmers has set up a sequel 'Beyond Randomized Clinical Trials' in September 2016, together with TNO in Artis.
5. Sabine Wernars and Saskia Koopmans organized a very successful Round Table discussion about the 'Cancer and Work' topic. They've worked this out in actions to be taken.

### Congress visits (amongst others):

1. Congress 'The Future of Genomic Medicine'. Tiel Jongmans, Jan Vesseur and Erik van Veenendaal went to the congress about data that Eric Topol set up in San Diego. A great conference where the latest developments in the field of Genomics and Big Data were reviewed. We're on the right path with our My Small Step initiative because most initiatives don't involve the patient as an active contributor.
2. 'Congress Health Data Paris'. Together with Jan Vesseur, Erik van Veenendaal went to Paris. Jan had received an

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invitation for the launch of a new pan European data initiative.

3. 'Personalized Medicine'. A congress supported by the EU Commission. Peter Kapitein gave a talk and asked why the research money is spend in the same way as it is for 10 years now. Shortly after that he was invited.
4. Global Alliance for Genomics and Health in Vancouver. Erik van Veenendaal and Peter Kapitein visited this imported 'Data congress'.
5. Peter Kapitein gave a talk for molecular biologists in Berlin about the patient's perspective on 'Personalized Medicine.'
6. Piarella Peralta and Ilona Schelle had a very strong and impressive role at the Sage Congress in Shenzhen; 'Know thyself and the environment in the digital era'.
7. Peter Kapitein gave a talk for radiologists in Valencia about the patient's perspective on 'Interventional oncology.' Shortly after this he was asked for the program committee for the 2018 meeting.
8. Peter Kapitein gave a talk about 'Value Based Health Care' in Putten.

## EU Research and Innovation.

Ilona Schelle and Peter Kapitein had an appointment at the EU Directorate for Research and Innovation and submitted a proposal to work together to achieve a different approach to cancer research. This proposal is based on the successful Discovery Network idea that has been previously introduced in 2011/2012 in Cambridge for the organoids of Hans Clevers and in 2015 in Amsterdam for Interventional Oncology.

## Sustainable finance for Inspire2Live.

In order to generate sustainable, independent funds for Inspire2Live, Erik van Veenendaal has started a Social Enterprise called WuWei4Life. The profits generated by WuWei4Life will be donated to Inspire2Live. WuWei4Life creates business opportunities in healthcare that are both profitable and improve healthcare for the patients.

## The Best Cancer Care / De Beste Kanker Zorg (DBKZ).

'The Best Cancer Care' now consist of A-Care / Cancer Rehabilitation, Fast Track Diagnosis, National Referral of patients and Surgery without Incision. We initiated the 'Organ Saving Treatment' and started with rectal cancer. Finally we hope to find funding for the 'National Map' with the best of the best when it comes to cancer.

## Concentration of Cancer Care.

We work on 2 initiatives together with specialists and health insurance companies. Oesophagus/Stomach cancer (our patient advocates Ineke Schouwstra and Ronald Hamaker) and Prostate Cancer (our patient advocates Johan Veenstra and Gaston Remmers). This is really a tough road to follow with a lot of obstruction by the specialists and hospitals but we are making progress. It will be a long lasting project but we have hope and conviction.

## Early Access to drugs.

We took over the position paper for Early Access to Drugs from the 'Stichting Eerlijke Geneesmiddelen Voorziening. It has been presented to the Dutch Minister of Health. We do the suggestion to immediately give the experimental drugs after phase 2 to patients with an unmet medical need. With a good register of the way a patients gets through the treatment we can skip phase 3 and give hope to these patients.

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## PA-meetings.

Several PA-meetings took place in 2016. Among the guests were Marcel Levi, the ceo of the Amsterdam Medical Center and Rob Pieters, the Medical Director of the Prinses Maxima Children with Cancer Hospital. These were very inspirational and constructive discussions.

## Memberships.

Inspire2Live was already a member of European Personalized Medicine (EPEMED) and because of the cooperation with PM-Connective we are automatically member of this Personalized Medicine and USA based organization as well. Peter Kapitein joined the advisory panel of PM-Connective.

In 2016 we became a member of the Global Alliance for Genomics and Health. A worldwide alliance for data sharing and the use of data for developing new treatments; collecting, analyzing and dissemination of health and patient data. People like Charles Sawyers set up this organization from New York (MSKCC) and Mark Lawler from Belfast (Queens University). A very representative organization.

Peter Kapitein joined the Executive Committee of the European Cancer Concord. A group of very influential patient advocates, clinicians and researchers from Europe. Inspire2Live was already a member.

## Finally

Peter Kapitein published a book called 'Hoe heeft het zover kunnen komen' ('How did this happen?'). This is well received in the press after being presented in the Amsterdam Medical Center to a patient, a general, a banker and a clinician.

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## In memoriam

Inspire2Live lost 1 patient advocate: Geert Bakker; <http://inspire2live.org/news/memori-am-geert-bakker/>



Many thanks for being and fighting with us Geert. We will never forget you. You're for always in our hearts.

Amsterdam, April 25<sup>th</sup>, 2016,

Erik van Veenendaal,  
President, CVO and patient advocate Stichting Inspire2Live

Peter Kapitein,  
CEO and patient advocate Stichting Inspire2Live

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## Balance sheet as at 31 December 2016

		2016	2015
		EUR	EUR
<b>Current assets</b>			
Receivables	1	470	22,336
Cash and cash equivalents	2	<u>156,621</u>	<u>162,179</u>
<b>Total current assets</b>		<u>157,091</u>	<u>184,515</u>
		<u>157,091</u>	<u>184,515</u>
<b>Foundation's equity</b>	3	157,091	172,096
<b>Current liabilities</b>	4	0	12,419
		<u>157,091</u>	<u>184,515</u>

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## Statement of income and expenses for the year ended 31 December 2016

		2016	2015
		EUR	EUR
Income	5	34,313	62,186
Operating costs	6	<u>49,619</u>	<u>56,271</u>
Operating result		-/- 15,306	5,915
Earned interest		<u>301</u>	<u>1,040</u>
Net result		<u>-/- 15,005</u>	<u>6,955</u>

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## Notes to the financial statements for the year 2016

### General

#### Applied standards

The financial statements were prepared in accordance with the provisions of Part 9, Book 2, of the Netherlands Civil Code and the guidelines included in "Richtlijn voor de Jaarverslaggeving 640, organisaties zonder winststreven" (non-profit organizations).

#### Activities

The principal goals of Inspire2Live are:

- \* stimulation of organizations with the primary goal to raise funds for the benefit of cancer research by organizing events;
- \* the set-up of worldwide, sustainable medical research;
- \* to stimulate and support scientific cancer research under all conditions, to let people be able to live Good, Happy and Healthy with cancer;
- \* to act and present herself, both internally and externally, as a non-governmental organization, and to carry out her activities in such a way that she will always be independent from governmental institutes;
- \* to be a non-profit organization.

Inspire2Live wants to achieve these goals by facilitating and inspiring people to organize sport events and by setting up activities which directly or indirectly attribute to the realization of her goals, including secondary commercial and profit generating activities, consistent with relevant laws, of which the profits will be used completely for the realization of the goals.

### **Principles for the valuation of assets and liabilities and the determination of the results**

#### General

If not stated otherwise, assets and liabilities are shown at nominal value.

An asset is disclosed in the balance sheet when it is probable that the expected future economic benefits that are attributable to the asset will flow to the entity and the cost of the asset can be reliably measured. A liability is disclosed in the balance sheet when it is expected to result in an outflow from the entity of resources embodying economic benefits and the amount of the obligation can be measured with sufficient reliability.

If a transaction results in a transfer of future economic benefits and or when all risks relating to assets or liabilities transfer to a third party, the asset or liability is no longer included in the balance sheet. Assets and liabilities are not included in the balance sheet if economic benefits are not probable or cannot be measured with sufficient reliability.

The income and expenses are accounted for in the period to which they relate.

The preparation of the financial statements requires the board to form opinions and to make estimates and assumptions that influence the application of principles and the reported values of assets and liabilities and of income and expenditure. The actual results may differ from these estimates. The estimates and the underlying assumptions are constantly assessed. Revisions of estimates are recognized in the period in which the estimate is revised and in future periods for which the revision has consequences.

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#### Receivables

Receivables are stated at nominal value less a provision for doubtful debts. Provisions are designated on the basis of individual assessment of recoverability of the receivable.

#### Result

The result is calculated as the difference between income and all the costs attributable to it during the year under review. The costs are calculated with due regard for the applicable valuation principles stated previously.

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## Balance sheet as at 31 December 2016

### Current assets

#### 1 Receivables

	2016 EUR	2015 EUR
Interest income	40	221
CZ subsidy grant	-	22,115
Prepayments Annual Congress 2017	430	-
31 December	<u>470</u>	<u>22,336</u>

#### 2 Cash and cash equivalents

	2016 EUR	2015 EUR
Rabobank 1356.22.883	1,190	730
Rabobank savings account	155,431	161,449
31 December	<u>156,621</u>	<u>162,179</u>

#### 3 Foundation's equity

	2016 EUR	2015 EUR
Balance as at 1 January	172,096	165,141
Result for the year	-15,005	6,955
31 December	<u>157,091</u>	<u>172,096</u>

A part of the foundation's equity is meant to cover costs related to the Discovery Network, including a EUR 110,000 donation of Stichting Tour de Concorde. A second part of the equity is meant to cover future costs related to the project My Small Step, following from a EUR 20,000 donation of Stichting Ice4Life.

#### 4 Current liabilities

	2016 EUR	2015 EUR
Trade payables	-	11,726
Other liabilities	-	693
31 December	<u>-</u>	<u>12,419</u>

### Off- balance sheet assets and commitments

Stichting Inspire2Live intends to pay Erik van Veenendaal for his work during the years 2012 until 2015 for an amount of EUR 243,525 including 21% VAT, only when sufficient funding will be available. At this moment, the funding available is

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meant to cover the costs of the Discovery Network activities. Therefore, no payment obligation as at 31 December 2016 exists.

#### Statement of income and expenses for the year ended 31 December 2016

##### 5 Income

	2016 EUR	2015 EUR
Subsidy granted	13,000	44,615
Donation Stichting Ice4Life	20,000	-
ComVision Sim services	-	15,000
Other income and donations	<u>1,313</u>	<u>2,571</u>
	<u>34,313</u>	<u>62,186</u>

##### Average number of employees

During the 2016 financial year, the average number of employees, converted into full- time equivalents on the payroll of the foundation, amounted to nil persons (2015: nil persons).

The board of Stichting Inspire2Live does not receive any remuneration and is independent of any scientific or fund raising organization from which the foundation receives subsidy or other grants. De Nederlandsche Bank allows Peter Kapitein to work three days a week for the foundation.

##### 6 Operating costs

	2016 EUR	2015 EUR
General costs	6,014	8,619
Project costs	<u>43,605</u>	<u>47,652</u>
	<u>49,619</u>	<u>56,271</u>

##### **General costs**

	2016 EUR	2015 EUR
Conference costs including travel	2,675	3,646
Travel costs	2,789	3,078
Various costs	550	<u>1,896</u>
	<u>6,014</u>	<u>8,619</u>

Conference costs refer to the visit of the Sage Congress in San Francisco. Travel costs consist of travel expenses in Europe and the USA.

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**Project costs**

	<b>2016</b>	<b>2015</b>
	<b>EUR</b>	<b>EUR</b>
Annual congress	27,108	20,624
Several congresses	6,226	-
Affordable drugs	8,371	-
Beyond RCT	1,236	-
My Small Steps	664	-
Discovery Network Intervention Oncology 2015	-	10,403
Lung cancer congress 2015	-	3,718
Brain tumour congress 2015	-	10,859
Pancreas congress, 2014	-	2,048
	<u>43,605</u>	<u>47,652</u>

Operating costs include VAT, which cannot be refunded by Stichting Inspire2Live.

Inspire2Live agreed that charges for temporary staff will not exceed EUR 100 per hour.

Amsterdam, April 25<sup>th</sup>, 2017

Stichting Inspire2Live

P. Kapitein, CEO Erik van Veenendaal, CVO

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