

# Stichting Inspire2Live

## Financial Report 2017

Version: April 16<sup>th</sup>, 2018



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# Supervisory board report

2017 might be entitled “The year of momentum”.

As you can read in this report, in 2017 a lot was accomplished and perhaps even more important, a change of general mindset has been started. This change, combined with the increasing influence of Inspire2Live in many organisations and initiatives will have its effect in the upcoming years.

Again, Inspire2Live has accomplished a lot in 2017. An overview is given hereafter in the Board report.

The Supervisory Board has no changes compared with 2016.

The Supervisory Board concludes that no irregularities or unwanted behaviour has taken place in 2017 and we endorse this Annual Report.

Amsterdam, April 16<sup>th</sup>, 2018,

R. Stekelenburg, Chairman of the Supervisory Board

## Board Report

This board report contains information about our financial year 2017. 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.

In 2017 Jeroen van Lierop joined Inspire2Live as the project manager and responsible for organizing initiatives that demand more structure than the daily activities of the patient advocates. Jeroen started organizing the successful initiatives concerning the prices of drugs.

Our organization now consists of 39 active patient advocates of which one in the USA, one in the UK, one in Sweden, one in Switzerland and one in Austria. Our patient advocates are highly educated, well informed and very 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 is highly recognized in initiatives around personalized medicine, the prices of drugs, the design of trials, influencing industry. These are all topics that are being discussed in parliament and through one of our patient advocates, Herman Otten a professional lobbyist, we find the members of parliament in The Hague and Brussel easily.

## New Patient Advocates in 2017.

Barbara and Mark Moss: <http://inspire2live.org/patient-advocacy-2/patient-advocate-barbara-moss/>

Bart Sikkens: <http://inspire2live.org/patient-advocacy-2/patient-advocate-bart-sikkens/>

Natalija Frank: <http://inspire2live.org/patient-advocacy-2/patient-advocate-natalija-frank/>

Henk Koopmans: <http://inspire2live.org/patient-advocacy-2/patient-advocate-henk-koopmans/>

Jeroen van Lierop <http://inspire2live.org/patient-advocacy-2/patient-advocate-jeroen-van-lierop/>

Jules Meijerink .... <http://inspire2live.org/patient-advocacy-2/patient-advocate-jules-meijerink/>

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## Reducing incidence.

Gaston Remmers works on a study for prostate cancer and nutrition. Gaston also runs the website for Platform Patient and Nutrition and participates in 'European Nutritional for Health Alliance', forming a European patient agenda around nutrition.

We contributed as one of the prosecutors in a legal case against the tobacco industry in the Netherlands. So far this initiative did not succeed in court but we do see a development towards a better climate for actions against smoking.

## Innovation of the clinical practice.

Visits are made by Ilona Schelle and Peter Kapitein, in cooperation with Herman Otten, with EU MEP's (for example Wim van der Camp and Annie Schreier-Pierik). Both help with what we call 'excellent cancer centers' and 'early access to drugs'. The politicians can influence government and give the patient the role we want and need.

Kees Braam has taken the initiative to set up immuno-therapy studies with Active Specific Immunotherapy (ASI) for cancer. Kees works with Tanja de Gruijl of the VUMC in Amsterdam and Jolanda de Vries of the RadboudMC in Nijmegen.

Huig Schipper is vice-chairman of the Patient Advisory Board of the Comprehensive Cancer Centers Netherlands. We provide solicited and unsolicited advice to the Executive Board of IKNL.

Marisca Urbanus delivered input for preliminary research EMC 'Early access to non-registered medicines'. She also prepared a plan for dialogue between PAs and industry, together with Kees van Schagen.

As the webmaster of the most visited cancer website in the Netherlands (more than 1 million visits per year), Kees Braam provides the content of [www.kanker-actueel.nl](http://www.kanker-actueel.nl) with up-to-date information on recent developments in the field of cancer.

Herman Otten is effective as a lobbyist in improving the availability of medicines. With Peter Kapitein and Jeroen van Lierop he's active to lower the prices through 'magisterial preparation'. This lobby is very effective and successful and the result is mainly thanks to Inspire2Live. The lawsuit that we want or may want to exert to ask for priority: the patient or the patent, has had many reactions and prosecutions.

There is good cooperation with the European Personalized Medicine organizations EPEMED and the American partner PM-Connective. Peter Kapitein and Ilona Schelle went to New York for this purpose and had some constructive discussions. Impressively, Inspire2Live was asked to give direction to these organizations. Our PA Piarella Peralta will be employed by PM-Connective for getting better diagnostics to the hospitals and therefore improve the quality of the treatments.

## Quality of Life.

Our PA's Saskia Koopmans and Sabine Wernars have realized an online magazine that will appear four times a year for employees and employers about cancer and work. Once again they organized the Breast Cancer Symposium and gave cancer and labor a lot of attention. Both PA's have been added to the Expert meeting on Late effects and work

PA Gerda Schapers (who sadly died in December '17) did a lot of important work as a webmaster and case manager for the website [www.opererenzondersnijden.nl](http://www.opererenzondersnijden.nl) (Inspire2Live is one of the two initiators of this site for surgery without incision). She was also employed in the Scientific Research Group of SPKS (patient group for colon cancer) and reviewed and assessed scientific studies for colon cancer. Finally she wrote in 3 journals for cancer patients a lot of book reviews, columns and interviews with doctors about new treatments.

## Quality of Care.

The initiatives for concentration of prostate, esophagus and stomach cancer resulted in the initiative to set up a Manifesto for  
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excellent cancer centers through its lobby activities. It concerns diagnosis, treatment planning, treatment and aftercare. We set this up along the lines of medical and psychosocial criteria and for the patient and her loved ones. When this Manifesto is ready (around April 2018), politics will be approached and we will enforce that cancer operations can only be performed in what are excellent cancer centers. This work is done by the PA's Ineke Schouwstra, Bart Sikkens, Henk Koopmans and Herman Otten.

Herman Otten took the initiative (among others) in 'European Affairs' (Inspire2Live is affiliated to the Agora platform, part of the EU Health Policy Platform of DG Santé) and for meetings between MEPs, the Directorate of DG Santé and Inspire2Live.

Jan Vesseur is a member of the IKNL advisory board, the BBMRI social advisory board, the MedMij Steering Committee, the 'Stimulans Fonds' (a fund for financing research into Multiple Myeloma and Waldenström's disease) and of the advisory board for the program of the International Forum, a congress of the IHI / BMJ in May 2018 in Amsterdam (3000 participants).

## Fundamental research.

From the ErasmusMC a proposal (Dik van Gent and Martine Jaegle) for funding by EPEMED. Involved are Ilona Schelle and Peter Kapitein. A grant is give of € 15.000,00.

Huig Schipper is a member of the advisory board at KWF, an assessment committee for research and implementation and a sounding board group of expensive medicines.

Huig Schipper is a member of the Working Group on the Influence of Scientific Research for advice on request for studies at, among others, MLDS, KWF, ZonMW and NOW.

Gerda Schapers participated in the research group of Jeroen van der Laak, Radboud: tailor-made treatment (software development that recognizes lymphocytes so that prediction of the disease progress can be improved).

Huig Schipper is involved in the design of the research in association with with MDOG and Winlove.

## Data.

Tjebbe Tauber is working with a representative of the GA4GH (Global Alliance 4 Genomics and Health) to link databases in the Netherlands (childhood cancer and possibly BRCA mutations) to the GA4GH.

Peter Kapitein was asked for one of the Digital Health Society working groups 'Governance Data' of an EU initiative of Estonia. It is about designing a governance model in which the patient owns and manages the data. It is important that the data is and remains available for research. The conclusions were presented to the European Parliament and DG Health. Peters will be replaced by Gaston Remmers.

Gaston Remmers is founder and director of the My Data Our Health Foundation and one of the designers of Holland Health Data Coöperatie.

Bert van Herk works with Hans Büller (Fair Medicine) on linking electronic patient records of healthcare providers.

Tjebbe Tauber allows data scientists to look at genetic datasets from cancer patients to provide researchers with a faster insight into the differences between patients who respond well and do not respond well to treatments. So far we have succeeded in helping Prinses Maxima Children Cancer Hospital in research on T-ALL leukemia patients.

Together with Tjebbe Tauber, Henk Koopmans and Bert van Herk, Erik is researching to what extent the 'All of US' initiative started in the US can be followed in Europe. All of US is an initiative that collects data from 1,000,000 people for scientific research. Data from sick, healthy, young and old people from all ethnic and cultural backgrounds.

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## **International Cooperation; our patient advocates abroad.**

Barbara and Mark Moss (UK) are members of the EUROPACOLON (42 European groups in work associated with raising standards for Colorectal cancer treatment), members of S:CORT (looking at the complex biology of bowel cancer samples collected from over 2000 patients). And they are bowel Cancer UK Patient Ambassadors: from the results of BCUK we have undertaken on a major study looking at research involved on the unmet need of colorectal cancer patients. Finally they wrote a book; 'Who's Been Peeping in my Bed?'

Karin Holm (Switzerland) focusses around understanding the current opportunities and logistics for a nationwide Swiss patient portal to access electronic health records. She has attended a lot of meetings and spread the news and importance of cancer patients.

Natalija Frank (Austria) works for PAN (an international patient advocacy non-profit organization (NGO), taking care of young people with cancer. They provide guidance and campaign for the best care, taking into account the needs of the affected persons and their relatives. Among a lot of other things, Natalija is active in Providing information, assistance and psychological support for social issues, matters of education and sexuality. And raises awareness for adolescents and young adults with neoplasia by established doctors and in society.

## **Congresses by Inspire2Live.**

'Annual Congress; 'The countless small deeds of the unknown people' 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. Shortly after the congress we already had several activities taken place.

We organized a congress about 'Quality of Life' in Amsterdam and were supported by Rabobank with the facilities. This too led to several actions. The congress was well received.

In Belfast we set up a 'Discovery Network for another approach of doing research'. With research and clinical institutes of Belfast, Glasgow, Madrid and Rotterdam we took the initiative 'Wikipanc' in which clinicians treat pancreatic cancer patient not according to the protocol but with phase 2 drugs. Based on the clinical expertise of the physician and the well informed patient, the treatment of patients is followed in a database and available for all participating institutes.

Sabine Wernars and Saskia Koopmans organized a successful 'congress on breast cancer' and the psychosocial aspects of living with breast cancer. They've worked this out in actions to be taken.

## **Congress visits:**

There have been hundreds of visits to symposiums, conferences and so on. The PA's of Inspire2Live are active in visiting (which is an important part in 'connecting') and during these congresses they play an active role in giving talks, taking part in panel discussions and asking sometimes irritating questions about matters concerning patients in healthcare.

## **PA-meetings.**

Several PA-meetings took place in 2017. Among the guests were Jan Hoeijmakers, researcher at the ErasmusMC and Ronald Brus, the ceo of myTomorrows. These were very inspirational and constructive discussions.

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## 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 2018. PA Piarella Peralta is since April 1<sup>st</sup> an employee of PM-Connective and responsible for patient advocacy in order to bring better diagnostics to excellent cancer centres.

In 2016 we became a member of the 'Global Alliance for Genomics and Health' (GA4GH). A worldwide alliance for data sharing and the use of data for developing new treatments; collecting, analyzing and dissemination of health and patient data. A very representative organization. PA Tjebbe Tauber works on data initiatives related to this organization.

Inspire2Live is a member of the European Cancer Concord (ECC). Peter Kapitein is member of the executive committee. ECC has merged with ECCO. The ECC is the policymaker for ECCO. This makes our influence bigger. The ECC is a group of very influential patient advocates, clinicians and researchers from Europe.

## Sustainable finance for Inspire2Live.

The financial position of Inspire2Live is good but not good enough. We can pay for every activity we do but we see that we have to do more and our environment expects more from us.

The support of an office manager, webmaster and also the payment of activities of some patient advocates who work more than 8 hours a week for Inspire2Live is necessary. 8 hours a week can be asked to invest in our organization. More is not ethical but nevertheless sometimes necessary. Paying for travelling within the Netherlands is a necessity (International costs for travelling are covered of course).

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.

More activities have to be setup for getting the financial resources that we need.

An estimate has been made and we think that our organization needs around € 350.000,00 a year.

## Finally.

Peter Kapiteins book 'Hoe heeft het zover kunnen komen' ('How did this happen?') has now been translated into English and is available via Amazon.com.

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## In Memoriam

Inspire2Live lost 3 of her patient advocates:

### Matthijs van Hall:

#### Patient Advocate: Matthijs van Hall (1954 – 2017)

Married to Betty, father of Odile, Sacha and Rutger and grandfather of Thaleia and Mathilde.

Professional career as program manager at the Ministry of Health and various other government agencies. Diagnosed with prostate cancer in 2010, Various treatments had little or no effect, momentarily good response to chemo treatment.

Active for several patient organisations. Most important mission: contribute to quicker availability of new drugs. "The whole system is designed for maximum security, the consequence is that it takes much too long to get new drugs to the patients, that the price of new drugs is much too high, and that patients are longer ill or die sooner".

Motto: "Life can't bring me down"  
(also the title of the CD of Matthijs his band the Fireball Express)



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Matthijs van Hall (1954-2017)

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## Chris Kerkhof:

Patient Advocate: Chris Kerkhof



CHRIS\_KERKHOF from BLONKFILM on Vimeo.

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## Gerda Schapers:

### Patient Advocate: Gerda Schapers

Since 2010 I am living with colon cancer stage IV . I had surgery in (2011), a TACE (2012) and a radio-embolisatie (2013): thanks to these last two minimal invasive treatments I am still living a healthy and fulfilled life. One of my goals is to make sure that those treatments are going to be possible for each cancer patient . That's why I'm on the Board of the SBBvK ( Stichting Beeldgestuurde Behandelingen van Kanker) and that's why I am patient advocate.

I am a teacher, I have been a teacher all my life. To teach and to learn is my passion. My love for learning sent me on a lifelong search for "how people learn". I learned about the importance of emotions in learning, about the functioning of the brain, about learning styles and learning organizations. And all about communication. I want to share with inspire2live forty five years of experience: twenty years in education, ten years as a manager in training and education companies and fifteen years as an entrepreneur.

I love to share this knowledge to make life better for cancer patients.



Gerda Schapers

Many thanks for being and fighting with us Gerda, Chris and Matthijs. We will never forget you. You're for always in our hearts and give us the energy to never ever quit.

Amsterdam, April 16th, 2017,

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 2017

		2017	2016
		EUR	EUR
<b>Current assets</b>			
Receivables	1	9,096	470
Cash and cash equivalents	2	<u>136,797</u>	<u>156,621</u>
<b>Total current assets</b>		<b>145,893</b>	<b>157,091</b>
		<u>145,893</u>	<u>157,091</u>
<b>Foundation's equity</b>	3	<b>145,752</b>	<b>157,091</b>
<b>Current liabilities</b>	4	<b>141</b>	<b>0</b>
		<u>145,893</u>	<u>157,091</u>

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## Statement of income and expenses for the year ended 31 December 2017

		2017	2016
		EUR	EUR
Income	5	48,712	34,313
Operating costs	6	<u>60,080</u>	<u>49,619</u>
Operating result		-/- 11,368	-/- 15,306
Earned interest		<u>29</u>	<u>301</u>
Net result		<u>-/- 11,339</u>	<u>-/- 15,005</u>

## Notes to the financial statements for the year 2017

### General

#### Applied standards

The financial statements were prepared in accordance with good merchant use and the provisions of Part 9, Book 2, of the Netherlands Civil Code. Inspire2Live however uses its own principles for valuation and determination of results, as allowed by Dutch law. These principles, however, largely correspond to the Guidelines for Annual Reporting for small organizations with no profit motive (RJ(k)-C1).

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## Activities

The principal goals of Inspire2Live are:

- stimulating organizations that aim to organize events for cancer research;
- setting up global collaboration to achieve medical research in a sustainable manner;
- promoting and supporting scientific research into cancer in all possible forms, so that people can live a happy, healthy life in harmony with cancer and getting cancer under control;
- to profile her behavior both internally and externally as a non-governmental organization ("NGO") and in the performance of her duties;
- maintain independence;

The foundation intends to achieve its goal by, among other things:

- promoting patient advocacy and supporting research;
- the development of activities that contribute directly or indirectly to the achievement of its objective, including ancillary commercial and profitable activities within the limits of what is legal permitted and the proceeds of which will become available at any time and are intended for achieving the objective.

## 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.

### 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 2017

### Current assets

#### 1 Receivables

	2017 EUR	2016 EUR
Interest income	3	40
Prepayments Annual Congress 2018	9,093	430
31 December	<u>9,096</u>	<u>470</u>

#### 2 Cash and cash equivalents

	2017 EUR	2016 EUR
Rabobank 1356.22.883	6,300	1,190
Rabobank savings account	130,497	155,431
31 December	<u>156,621</u>	<u>156,621</u>

#### 3 Foundation's equity

	2017 EUR	2016 EUR
Balance as at 1 January	157,091	172,096
Result for the year	-/- 11,339	-/- 15,005
31 December	<u>145,752</u>	<u>157,091</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

	2017 EUR	2016 EUR
Bank charges payable	22	-
Other liabilities	119	-
31 December	<u>141</u>	<u>-</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 meant to cover the costs of the Discovery Network activities. Therefore, no payment obligation as at 31 December 2017 exists.

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## Statement of income and expenses for the year ended 31 December 2017

### 5 Income

	2017 EUR	2016 EUR
Subsidy granted	47,817	13,000
Donation Stichting Ice4Life	-	20,000
Other income and donations	<u>895</u>	<u>1,313</u>
	<b><u>48,712</u></b>	<b><u>34,313</u></b>

During the 2017 financial year, the average number of employees, converted into full-time equivalents on the payroll of the foundation, amounted to nil persons (2016: 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

	2017 EUR	2016 EUR
General costs	12,291	6,014
Project costs	<u>47,789</u>	<u>43,605</u>
	<b><u>60,080</u></b>	<b><u>49,619</u></b>

#### **General costs**

	2017 EUR	2016 EUR
Conference costs including travel	-	2,675
Travel costs for connection	12,015	2,789
Various costs	<u>276</u>	<u>550</u>
	<b><u>12,291</u></b>	<b><u>6,014</u></b>

Conference costs refer to the visit of the Sage Congress in San Francisco (2016). In the year 2017, the costs for the visit of this congress are included in the travel costs for connection. The travel costs for connection consist of travel expenses in Europe and the USA for visiting several congresses and people. From 2017 these costs are collected and shown under this category, while they were included under the project costs last year.

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**Project costs**

	<b>2017</b>	<b>2016</b>
	<b>EUR</b>	<b>EUR</b>
Annual congress	<b>44,007</b>	<b>27,108</b>
Discovery Network congress	<b>189</b>	-
Quality of Life congress	<b>2,929</b>	
Several congresses	-	<b>6,226</b>
Affordable drugs	-	<b>8,371</b>
Beyond RCT	-	<b>1,236</b>
My Small Steps	<b>664</b>	<b>664</b>
	<b><u>47,789</u></b>	<b><u>43,605</u></b>

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

Inspire2Live agreed that charges for temporary staff will not exceed EUR 80 per hour.

Amsterdam, April 16th, 2018

Stichting Inspire2Live

P. Kapitein, CEO & Erik van Veenendaal, CVO

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