



Inspire2Live Achievements to be proud of

May 12th, 2020

Inspire2Live was founded in 2010 and has achieved a lot. Sometimes directly as a result of our own activities, sometimes because we initiated an activity or project. All our patient advocates are active in their own profession or as a volunteer for Inspire2Live. These activities result in the following achievements.

2019

A big disappointment was that we did not find one member of parliament that was willing to ask the minister of health to ask the human rights committee of the Netherlands whether the government was violating human rights with the allowance of the selling of tobacco. We found however a barrister that is looking for possibilities to bring the government to court for violating the human rights. 'Do not forbid smoking but forbid the selling of tobacco'.

Last year there was a restart of 'Surgery without Incision'. We work closely together with two interventional oncologists from the VUMC.

Inspire2Live initiated a project for pancreatic cancer & glioblastoma. Of course, all activities in close cooperation with external experts from AMC, Hartwig Medical Foundation, ErasmusMC, insurance and industry. We will treat patients based on the output of Whole Genome Sequencing. We are convinced that we can decrease the overtreatment and make a good step in the direction of Personalized Medicine and for the first time in decades make progress for the patients with these diseases.

We work together with the AMC on an initiative to give people (not patients) with a hereditary determination for pancreatic cancer an artificial pancreas and remove the existing pancreas to prevent cancer.

The EU started with the discussion on Horizon Europe (the successor of Horizon 2020). Patient advocates are not involved in the Expert Group. Herman and Peter were in discussion with the EU to broaden our influence. A letter to the EU commissioner Moedas (Research and Innovation) has been written. We contributed to the result that Bettina Ryll, one of the great patient advocates from Denmark is now in the Expert Group.

Inspire2Live works on an initiative to study pain in pancreatic cancer patients. 'If we can take away the pain, we give these patients 6-12 months more with a good quality of life'. We work with researchers in the USA, the UK, the Netherlands and Italy. But hopefully a finding in the Netherlands will bring an end to the suffering of these patients.

IQVIA, the biggest clinical research organization in the world and experts in data analysis, supports us with data for the Excellent Cancer Centres. As a start, because since then we extended the relationship with IQVIA with a workshop on our and their data initiatives and see whether we can work together in more areas.

We brought personalized diagnostics to the patients, using data science and participated in the LUMC hackathon on melanomas. Finally, we organized an experiment with ABN/AMRO & Prinses Maxima Center for Children Oncology to accelerate DNA sequencing for patients (goal is to bring calculation time from 5 to 2,5 day).

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Our Discovery Network in Boston led to the cooperation of Laura van 't Veer (University of San Francisco) and Valter Longo (University of Southern California and University of Milano) on dietary restrictions. Also, Ronald Plasterk told us that his initiative on Frame Therapeutics (based on frameshifts in the protein structures) got a boost because of that meeting. And as a result, Lex Eggermont and Laura van 't Veer are in his advisory board.

Our *Annual Congress* 2019 (January 30, 31 and February 1) has taken place and was a big success with a lot of connections and activities that came and come out of it. The most promising is 'Open Source Pharma'. We were invited by Jaykumar Menon to set up a European division and we are as we speak working on that. Also, the cooperation with the Hartwig Medical Foundation was fruitful. The result is an initiative that got a majority in Dutch Parliament for Whole Genome Sequencing for all metastasized patients. A link to the site:

<http://inspire2live.org/inspire2live-annual-congress-2019/> and of course more information about the magazine, click here: <http://inspire2live.instantmagazine.com/inspire2live/inspire2live-annual-congress-2018/cover/>

We had an awesome Annual Congress 2020 with lots of visitors. The theme is '*Eminence, Arrogance, Ignorance and Evidence*'. All presentations are recorded and also all of the speakers gave an interview. Here's the link to all this: <https://inspire2live.org/our-congresses/past-annual-congresses/inspire2live-annual-congress-2020/> Piarella organized the workshop on In Vitro Diagnostics Regulations (IVDR) in collaboration with Diaceutics as a preconference event for the Annual.

On Friday, October 4, Stichting Jij Speelt de Hoofdrol and Inspire2Live organized a day from patients for specialists. Title was '*Step together in the new world*'. A great success that certainly deserves to be copied. Communication between doctors and patients, complementary medicine and cancer and work were some of the topics that were discussed.

October 4th, a two days' seminar was organized by Inspire2Live in cooperation with the foundation 'Jij speelt de Hoofdrol'. Over 50 attendants (para)medicals and (ex)patients. Topics were: Communication between (ex) patient and medical, complementary care and holding job(s) during diagnostic, treatment and recovery

We initiated the possibility for fundraising through Facebook. When people want to celebrate their anniversary, they can ask for contributions for Inspire2ive.

We re-established the relation with KWF. KWF became our partner for our Annual Congress and we hope to extend this relation.

We launched Inspire2Go January 2nd 2020. We started with 'Excellent cancer centres'. The best centres for the 15 most common cancers according to the oncologists themselves. More initiatives will follow. We launched the Inspire2Go website in March. We had planned March 18th a session with Dutch members of Parliament to promote our website and the Excellent Cancer Centres. Due to Corona, this failed and now we hope that this session can take place in September/October.

Inspire2Live is successful in a great part of Europe. Our network is strong and many initiatives are taken or inspired by us. But far too little is being done and it is not done good enough. If we just execute what we know, we can even improve the survival percentage in the Western world. Probably, we could reach a little over 70%. But

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we still do not execute what we know and when you do not execute what you already know, it's a bloody scandal (David Lane). What's preventing us? We need active cooperation and participation of all the stakeholders in the medical industrial complex to be successful in our global quest. When one of them acts alone we will not be successful, or it takes too long. We are building 'Inspire2Live Hubs'. Working groups of scholar activists and patient advocates that connect the stakeholders of the medical industrial complex. To put pressure where needed, to help where needed, so that we do right by the global patient. We already have one hub in Europe and we start with hubs in Africa, Asia (Singapore, South and Middle America, USA East Coast and USA West Coast.

2018

We rewrote the vision document on reducing incidence: <http://inspire2live.org/wp-content/uploads/Reducing-Incidence-vision-document.pdf>. This is for creating/enhancing awareness and focus in Den Haag and Brussel.

We are also involved in two lawsuits concerning the tobacco industry.

- One of Benedict Ficq against the Public Prosecution Service (the Article 12 Sv procedure) at High Court in Den Hague. In addition to the question whether the tobacco industry can and must be prosecuted, the question also arises whether Inspire2Live (like many foundations and associations with us), is receptive to this case. On December 6th the High Court decided that the answer to the first question was 'no'. The Public Prosecution Service is not able to and not obliged to prosecute the tobacco industry. And so was the answer to the second question. It was 'no'. Inspire2Live is inadmissible to this case.
- The second is the enforcement request at the NVWA (together with many other interested parties). This request was rejected and it was also stated here that Inspire2Live is inadmissible (with many other parties). This inadmissibility has been disputed by me with a number of arguments. We received a positive response from lawyer Phon van den Biesen. Before we can go to court, we first have to go through the administrative enforcement process, so first a notice of objection against the rejection was prepared by Van den Biesen. The hearing about this in The Hague was November 29th.

Prevention is still a topic that needs more of our attention of Inspire2Live. We are not well equipped with patient advocates that want to pick up this important topic. A serious new attempt however will be made in 2020.

During one of our sessions at the Annual congress we discussed quicker ways than Randomized Controlled Trials for introducing treatments into clinical practice, given the enormous amount of historical patient and treatment data for some types of cancer. One of our patient advocates is preparing a scientific article on this topic together with an epidemiologist.

Together with the 'Vereniging Innovatieve Geneesmiddelen' (the branch organization for pharmaceutical companies in the Netherlands) we are setting up a round table between patient advocates and industry. We drafted an invitation for the first roundtable in November/December.

After the death in 2017 of a key-player of 'Surgery without incision', our patient advocate Gerda Schapers, we had to revitalize this important initiative for patients that need interventional oncology. It appears to be an uphill battle but together with some very active interventional oncologists we will make it a success and probably even expand it with extra functionality for patients. We will start in the mid of January 2019, with the website 'surgery without incision' www.opererenzondersnijden.nl The website informs patients about intervention radiology.

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In April, we presented the petition 'From "We do everything"-hospitals towards 'Excellent Centres' to the Dutch parliament. It was well received and the minister of health had to answer several questions. We were not satisfied with his answer that it was a good petition but that he wants the professionals to look at it and implement it. It is our experience that these professionals are distributed over too many institution, and therefore lack cohesion and urgency, and therefore will not act. In 2019, we will continue with this important topic because it saves lives of many patients when treated in the right cancer centre. We see a growing appeal to our organization from patients and relatives, and we advise many via telephone consultation, e-mail and sometimes visits at home or doctor about second opinion and choice of hospital that's best for their specific type of tumour.

I2L has become a partner in EU-subsidized projects of specialists' organizations, looking at possibilities in the field of setting up and implementing guidelines for urology and cancer, together with Karin Plass (European Alliance for Urology). Patient advocates within the project will be reimbursed. It is a long shot but it looks promising.

We brought together all the stakeholders involved for another approach of treating patients with glioblastoma and pancreatic cancer. In some cases, they can be treated with other drugs, notably Phase2 and all registered drugs (EMA or FDA). The big hurdle to take is reimbursement in this. We asked health insurance companies and industry to join. Together with oncologists and surgeons we can really contribute to enhance the treatments and speed up the process of finding new treatments. This initiative is a direct result from the Discovery Network we organized in Belfast November 30 and December 1 2017.

Our initiatives and interventions in the national debate on the pricing of medicines was well received and had a good spinoff. Several organizations and media asked for contact and cooperation. We're continuously (re)thinking our strategy for getting the right treatments to all patients. This is our main goal in the discussion on pricing. A great success and for sure partly because of our work the Dutch parliament approved a motion for magisterial preparation (preparing the drug by the hospital itself instead of buying it from the pharmaceutical company. This will put pressure on the industry. For this topic, we were invited in a hearing at the EU parliament. This was very successful and warmly welcomed by the MEP Annie Schreier-Pierik. She emphasized that this hearing was set up because of the initiative of the patient advocacy group Inspire2Live. Before this hearing, she had never seen one of the other participants.

Together with myTomorrows we work on the possibility of getting another CAR-T treatment to the patients via the AMC/VUMC. Milteney, a German Biotec, has an improved method for 1/5 of the Novartis or Gilead price. The AMC/VUMC and Prinses Maxima Center for Child oncology are very interested in doing a trial. If this succeeds many patients will be able to receive this promising treatment.

In June 2018, the NOS (Dutch Broadcast Foundation) published a [news article](#) on the ATE (Awareness Through Experience) COOKIES ®, developed by the HungerNdThirst Foundation (run by one of our patient advocates) as an educational tool on taste alteration and nutrition. The ATE COOKIES ® mimics the metallic taste some patients experience during cancer treatment. This helps friends, relatives and medical staff to understand this issue. In September, the foundation started negotiations to bring the cookies to the global oncology market.

Inspire2Live participated in the proposal for prehabilitation from the Maxima Medical Center in Veldhoven. We contributed to the development of an implementation approach for the 'Fit voor Kanker' project, culminating in a

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request for funding to ZonMW. The request has not been granted, but together with MMC-Veldhoven we will keep up our efforts to expand this important topic to all patients that need prehabilitation and/or rehabilitation. A wish that we have since the founding of Alpe d'HuZes.

One of our patient advocates is developing the site www.oncoformance.nl with information about physical activity in relation to cancer. Next to this he also develops the site www.sportenkanker.nl which is an inspiration site about how top athletes dealing with cancer.

We are very active to inform employers and employees about reintegrating with / after cancer and inform patients about self-direction before / during / after their treatment. In December of this year we have achieved a cooperation between our Cancer Labour group, the Group Labour and Cancer and the University Medical Center of Amsterdam to organize a 'National Cancer and Labour Day' in 2019. We will bring employers and employees together to improve the situation of cancer patients at their workplace and to avoid losing jobs and income.

There is always a time pressure for patients when visiting their primary care providers. There are guidelines on survivorship but a lot of primary care providers are not aware of them and there is no coordinated care. Inspire2Live investigates the guidelines that are being developed, because there is a lack of communication between primary care providers and specialists. As patient advocates we would like to draw a cancer survivorship care plan.

One of our patient advocates is director of Toon Hermans Huis Tiel, a place for everyone who has been touched by cancer to meet companions and take part in activities. She started Toons Kids-club for children in the age from 6 till 14. They don't expect the children with cancer but those whose parent or close family member has cancer. Ine van der Laan, child psychologist, will start this group with the children of our existing 'guests' of the Toon Hermans Huis.

Together with the Secretary General of the Dutch Ministry of Health one of our patient advocates is looking for boards in care institutes that need a patient advocate in their board. We do believe that health care will improve when patient advocates are not just part of the discussion but also part of the decision. 'When you're not at the table you're on the menu'.

We are addressing patients from Antoni van Leeuwenhoek Hospital to deliver their data for research purpose.

We organized a hackathon at the ABN/AMRO event 'Beyond Banking' with 2 groups of young people and professor Peter van der Spek from the ErasmusMC in Rotterdam, to analyse data from lung cancer patients to predict the best treatment. We work on an algorithm to make this work in a clinical setting. This initiative gets so much attention that it will grow and become a very important initiative to improve treatments. We learn how data, data scientists and medical researchers together can help patients.

Ghada Ibrahim has taken over the role of Karin Holm as the leading patient advocate of Patient Advocates for Cancer Research & Treatment (PACRT), Geneva, Switzerland.

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The work of Seun Adebisi in the USA for the bone marrow registry is of great value. It is very important for Afro American people to have more potential donors. 'We have recruited 143 new bone marrow donors through drives in Abuja, Lagos and Zaria. We are planning our biggest drive yet in August, where we hope to recruit over 1,000 donors.'

Jeffrey Waldron has become 'our man in Boston' and helps us in organizing the discovery Network in Boston, February 2019.

Barbara and Mark Moss are extremely active in EuropaColon the organization for Colon Cancer. Barbara also is taking part in the working group for research on new biomarkers.

Natacha Bolaños is providing a lot of support to Lymphoma Coalition Europe which includes a significant time invested in discovering challenges at European countries level, promoting patient engagement, exploring potential collaborations to make them stronger or more sustainable. In addition, she joins two important roles at country level in Spain: CAR-T institutional working group - Plan for the approach of Advanced Therapies - Basket of Services SNS and Pharmacy – Ministry of Health Spain and General Patient Alliance – Secretary

Natalija Frank in Austria plays a great role in the Workshop on Clinical Research in Ghana and PAN's Awareness Project #TheEyeOfGuardian. Visit their website www.pan-austria.org

Jolanda van Rooijen is doing a lot of work in complementary treatments for breast cancer patients in Sweden. Among them plastic surgery.

Our own Annual congress was extremely well received. The 'out in the city' and 'combination of experienced hand and the beginners mind' was a big success. Approximately 135 participants visited the congress. Several activities have been initiated because this congress.

We co-organized the congress 'BeyondRCT: towards co-operative citizen science in Food and health'. This was well received and visited by around 100 participants, 25-26 sep 2018.

There have been dozens probably more than a hundred visits to symposiums, conferences and so on. On most of these visits our patient advocates give talks on all topics related to cancer. We see a growing interest in our patient advocates to give their opinions and contribution. We also see that there is a growing tendency among patients, medical professionals, scientists and institutions and NGO's to seek and to activate the "Voice of the patient" in discussions of policy and implementation.

We had the following PA-meetings:

- Ronald Brus, ceo of MyTomorrows, about another way of access to drugs.
- Edwin Cuppen, scientific director of Hartwig Medical Foundation, about Whole Genome Sequencing.
- James N'Dow, surgeon from Aberdeen, about guidelines.
- Jan Dekker, ceo of FoodFirstNetwork, about healthy food and prevention.
- Discussion session about drug pricing with Celgene and lead by Inge Diepman.
- An 'internal' PA-meeting about our mission, vision and communication.

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Inspire2Live is a member of the European Cancer Concord (ECC). ECC has merged with the European Cancer Organization (the organization for all stakeholders in the field of cancer research and treatments; ECCO) in 2018. The ECC is now an important policymaker for ECCO. This makes our influence bigger. The ECC is a group of influential patient advocates, clinicians and researchers from Europe.

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 1st an employee of PM-Connective and responsible for patient advocacy in order to bring better diagnostics to excellent cancer centres.

It's good to see that the relation with KWF improves now a new director has been appointed. There have been several meetings with employees from KWF with PA's from Inspire2Live in 2018.

We are working on a new team for public relations and a new vision in how to do public relations for Inspire2Live. 2 new members (professionals in PR and marketing) joined the team.

2017.

We worked on a study for prostate cancer and nutrition. One of our patient advocates 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.

We are now in good contact and relation with several members of the European parliament as well as with members of the parliament of the Netherlands. It's our goal to get more influence on a political level in order to achieve more for patients. One of our patient advocates is an effective lobbyist in The Hague and Brussels.

We work on a platform for patient advocates and industry to inform each other and to think of different initiatives.

The initiatives for concentration of prostate, esophagus and stomach cancer resulted in the initiative to set up a Manifesto for 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.

We allowed 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.

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This data initiative with Machine Learning and Artificial Intelligence is becoming more and more visible and important.

Two of our patient advocates 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.

In Switzerland) we focused 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.

In Austria, we worked 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.

Our 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 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.

Together with the foundation 'Jij speelt de hoofdrol' we organized a successful 'congress on breast cancer' and the psychosocial aspects of living with breast cancer. This has been worked out in actions to be taken.

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.

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.

2016.

Our 5th 'Annual Congress; 'Walk the extra mile for the patient' took place, again, at the Royal Academy of Science. We had a lot of positive reactions. Most people like the active interaction between the various

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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.

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.

With 'Beyond Randomized Clinical Trials' we've 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. We also set up a sequel 'Beyond Randomized Clinical Trials' in September 2016, together with TNO in Artis.

A very successful Round Table was organized as a discussion-session with good and representative speakers about the 'Cancer and Work' topic. They've worked this out in actions to be taken.

Patient Advocates 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.

In order to generate sustainable, independent funds for Inspire2Live, we 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' 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.

We work on 2 initiatives together with specialists and health insurance companies. Oesophagus/Stomach cancer and Prostate Cancer. 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.

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 patient gets through the treatment we can skip phase 3 and give hope to these patients.

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.

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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. We 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, analysing 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.

We 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.

We were asked to join the executive committee on drugs pricing of the European Hematology Association. An immediate result of our congress Affordable drugs.

We facilitate cancer patients either to stay at work or to get back to work. Workshops with the stakeholders and initiatives have been taken.

Inspire2Live is involved in (international organizations and journals: Member of European Cancer Concord (ECC), Member of European Personalized Medicine (EPEMED), The global Alliance for Genomics and Health (GA4GH), Editorial Committee of Annals for Translational Medicine, The European Hematology Association, Peer reviewer for British Medical Journal (BMJ), Program board of PA course of the EORTC, as well as other activities of the EORTC.

Peter Kapitein published a book called 'Hoe heeft het zover kunnen komen' ('How has it ever come to this?'). 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.

Our patient advocates are asked many times to speak at conferences. This is launched as an important initiative; 'If about us not without us'. When issues are being discussed in health care patients have to be involved and take the decisions.

Our patient advocates do not only speak at congresses they also visit more and more congresses to improve the visibility of patients and patient advocates.

2015.

In January, we organized our annual Congress 2015 in honor of AIDS clinicians, researchers and AIDS activists Joep Lange and Jacqueline van Tongeren who both died in the MH17 killing; 'Breaking the barriers for patients'. This congress was more or less a cooperation with the AIDS activists of the eighties and nineties of the former century. We 'learned' from them. Over 100 people from different backgrounds discussed this important topic and came up with ideas and solutions.

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We brought together world leaders of the field of Interventional Oncology (surgery without incision). Together with them we work on the implementation of this important new technique of doing surgery for all patients that are eligible for this treatment.

We organized a successful theme congress on 'Lung Cancer'. Several initiatives are taken after this congress.

For 'Brain Tumor' we organized a theme congress. This is tough to follow up. The specialists are very diverse in their opinions what to do but we are determined and still work (as we speak may 2017) on a way to help these patients.

Every congress is based on a very important principle; bring together the right people to solve a big problem for cancer patients.

Inspire2Live is thinking and sometimes already working on Discovery Networks for 'Personalized Medicine and for 'Immunology'.

Inspire2Live initiated in the Netherlands a website where patients receive advice for the best treatment for metastasized colon cancer to the liver: 'traditional surgery' or 'surgery without a knife'. The latter is non-invasive (patient-friendly) and has limited side effects. It probably will be taken in the basic care of the health insurance companies. This is due to our work in cooperation with the innovative radiologists.

The Dutch Cancer Society (KWF) spends over 80 million euros on research each year. Three of our patient advocates are actively taking part in the decision-making process for research in the patient board at KWF.

We work with insurance companies to concentrate cancer care centers in the Netherlands.

We want reimbursement for off label drugs. We are in discussion with the Department of Health and health insurance companies.

We have taken action to make drugs available on the basis of compassionate use for patients who have no alternatives left. We are now in discussion with the Minister and those involved in the Department of Health.

Inspire2Live is involved in SPECTA; the EORTC initiative of new and more patient oriented trial design.

We are working on getting all patients into clinical trials. Our aim is to create more awareness for trials amongst patients and clinicians by lobbying for the trial registers to be more patient focused instead of researcher focused by using simple language, for example.

We are urging CEO's of University Medical Centers to always ask themselves 'Is what I do in the best interest of the patient?' with regard to their policy making.

Inspire2Live works on the 'Mission of Mark'. Mark was journalist and Patient Advocate who publicly shared his journey in search of a cure for his cancer. This mission is bringing the patient more into the center of research and

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cancer care. We will organize a day with special focus on the patient (wearing red bands) and we are setting up a project to inform and facilitate patients to donate their medical data to an open source database. This project 'My Small Step' is about patients saying: "That's my data, use my data". This is the Inspire2Live call for action to patients to sign an Informed Consent and donate their data for research.

2014.

Setting up a Network Discovery for Interventional Oncology. We brought together Intervention Oncologists/Radiologists from the USA, France, Germany, Italy, Israel and the Netherlands in Amsterdam.

We started to establish a Discovery Network for Immunology. We will focus on new and innovative aspects of Immunology.

Securing the studies that have been set up in the Discovery Network Targeted Medicine, which has led to a nice article in Cell in which Inspire2Live is mentioned as the party that has brought the group of scientists and clinicians together and making it possible.

We organized a theme congress on Pancreatic cancer, which resulted in the Pancreas Patient Platform Netherlands. Inspire2Live initiated this and asked the Lisa Waller Hayes Foundation to host this PPPN. This platform will act as a model for other countries in how to organize the best possible care for pancreatic cancer patient.

We initiated a Patients Information Platform for better, specific and more patient friendly treatments. This is part of our concept of the Best Cancer Care.

We initiated a letter along with other patient organizations to Minister of Health, Edith Schippers, about Compassionate use of new drugs.

We initiated a letter to ZINL about Operating without Incision. The treatment Radio Embolization was requested to be included in the basic health insurance policy.

2013.

In 2013, Inspire2Live had 6 events:

- Alpe d'HuZes in The Netherlands,
- The Pocho in Costa Rica,
- Skate4Life in Norway,
- Tour de Concorde in France,
- Ven2-4-Cancer in Belgium and
- TumbleUp4Life in the UK.

At the end of 2013 Inspire2Live stopped the activities for setting up and supporting existing events for fundraising in other countries because of the media frenzy and the subsequent decision to focus on Patient Advocacy rather than Fundraising.

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In 2013 Inspire2Live started a small group of patient advocates in Switzerland. It is planned to work with groups in other countries as well.

In January 2013 Inspire2Live had her third annual conference 'Reducing Incidence'. A gathering of patients, clinicians and researchers came together and worked for 2 days on ideas of making a difference on prevention. The conference was a big success and had a lot of enthusiastic reactions. Inspire2Live's guest of honor, professor Bob Weinberg, made a beautiful statement and compliment: 'Your patient advocates are by far more effective when it comes to reducing incidence than a scientist can ever be'. It's of great importance because this statement makes emphasizes that only through cooperation based on equality between patients, clinicians and researchers, the fight against cancer can be won!

In 2013 Inspire2Live received the 501(C3) status for Inspire2Live INC., a dormant foundation in the USA, which allows fundraising with tax reduction in the USA.

In 2013 Inspire2Live received an amount of EUR 110,000 from Tour de Concorde, what will be used for several activities in 2014, 2015 and 2016.

2012

Since we started in 2011 with our program to get cancer under control in 10 years we encountered a lot of skepticism. However nowadays there is a strong belief that it can be done much faster than in 50 years (which has been told for the past 40 years). Well known scientists nowadays tell us that they most certainly have solved the problem from a scientific point of view in the next 10 – 20 years. Inspire2Live has initiated this discussion.

2012 has had the second annual conference. 'The Young Ones'. We copied the first edition of 2011 but now with participants not older than 40 years. The conference was very inspiring.

In 2012, we had 3 new events:

- In Costa Rica we initiated the Pocho: 8 times in one day the Poas volcano for Funda Cancer.
- In Norway we had a Skate4Life event. A 200-kilometer skate event near Lillehammer.
- In France we started with Tour de Concorde. A group of cyclists cycled the entire Tour the France one day ahead of the real Tour de France. This edition was only with Dutch bike riders.

This means next to Alpe d'HuZes, Ven2-4Cancer and Tumble4Life 6 events for the PR, Awareness and Fundraising for cancer.

Our quest started in 2011 and our program for getting cancer under control, Understanding Life!, was updated as it will be done yearly.

We initiated in 2012 the clinical trials of:

- Charles Sawyers; prostate cancer,
- David Tuveson; pancreatic cancer,
- José Baselga; breast cancer
- Adrian Harris; Angiogenesis.

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The projects of Charles Sawyers, Dave Tuveson and José Baselga had some impediments because of drugs that they proposed to use in their trials where withdrawn by industry. A new drug was found for replacement in the project of Charles Sawyers and David Tuveson. José Baselga decided to withdraw.

We have done a lot of work in setting up The Discovery Network around the organoids of the Dutch Scientist Hans Clevers. In 2012 colon cancer and prostate cancer programs have started. A lot of progress has been made with the pancreatic organoids in the second phase of the program. The Hubrecht laboratory of Hans Clevers has already found solutions for lung and breast organoids and clinical trials are defined for these types of cancer as well. This is a major achievement of Inspire2Live, for it is now possible to do trials based on 3D life human tissue ex vivo made out of human tumor stem cells instead of cell lines and mice! Inspire2Live initiated and financed the Proof of Concept for this program in 2013. In this POC Hans Clevers (producing organoids), David Tuveson (pancreatic cancer), Charles Sawyers (prostate cancer), Mike Stratton (drug screening), Matthew Meyerson (sequencing), Hans Bos (colon cancer) and Stephen Friend (data collection and –analysis) worked together This intercontinental cooperation between some of the world's best institutions is a major breakthrough for finding better and more effective therapies for patients worldwide.

We initiated the set-up of a health literacy program in the Netherlands. In cooperation with the University of Groningen and the Max Planck Institute for Humanities in Berlin we developed a curriculum for a healthy life style for children between 8 and 11; the most vulnerable age when it comes to learning about a healthy lifestyle.

Inspire2Live, in cooperation with several countries in Africa, started the initiative to make sure that we don't stop with implementing new treatments when it comes to lower income countries. PECA, (Project for the Eradication of Cancer in Africa) in Nigeria is the first initiative for this activity.

In 2012 we started with a group Patient Advocates in the Netherlands. These Patient Advocates are highly educated, well-informed, eloquent and motivated patients, cancer survivors and loved ones from diseased patients. The mission from this group is 'To realize the best cancer care and the access to this best cancer care'. On our website The Manifest as well as our Vision Document are available. We have a strong belief that this will strongly change and improve the quality of the cancer care in the world.

In 2013 we will set up a group of Patient Advocates in Switzerland. We will work on groups in France, Germany, Austria and the UK as well. Essential in this work is the cooperation of patients, clinicians and researchers on an equal basis.

2011

In 2011, we organized the conference Understanding Life. We invited 50 of the best researchers and clinicians of the world and let them work together on the question: 'How can we get cancer under control within 10 years?' 2011 was actually the first year with a lot of activities for setting up the research that will get cancer under control before 2021. We started our 10-year program 'Understanding Life!' on January 17th. In 2010, we started the search for funds for this program. In 2011, we continued our quest but it became clear that raising funds for projects that are set up internationally is not easy. Foundations and governments want to pay for research conducted in their own country and not for research done in others. Therefore, we changed our concept. We now

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bring together researchers and after setting up the meetings with researchers and define what studies need to be done we will bring the funders in.

In 2011, we worked further on implementing events in other countries based on the success of the Dutch initiative Alpe d'HuZes. 'What can be done in the Netherlands can be done in all the countries of the world'. Cancer does not discriminate and it is needed to connect patients, clinicians and researchers all around the world for our common goal. For the first time, we organized Tumble4Life in the UK. With this event, we raised funds for Cancer Research UK.

In 2011, we had the first discussions about setting up a third part of our organization: Patient Advocacy. This is implemented in 2012.

We've launched four innovative, phase II clinical trials, in which new combinations of drugs and approaches to controlling cancer are tested. The awarded clinicians and their institutions are 1) Jose Baselga, at Mass General Hospital, Boston, on a new breast cancer treatment, 2) Charles Sawyers from Memorial Sloan Kettering Hospital, New York, on a new prostate cancer treatment, 3) Dave Tuveson from Addenbrook Hospital at Cambridge University, on a new pancreas cancer treatment and Adrian Harris, from Oxford Medical Hospital, Oxford, on a new angiogenesis inhibition approach. The trials are well underway and show good progress. The scientists were informed and the contracts as well as the research were prepared in the end of 2011. The actual launch of the programs was in 2012.

2010

We have built a program plan for getting cancer under control: 'Understanding Life'. This plan has been discussed and worked on during the conference of January 2011 and finalized. You'll find this program plan on our website.

We transferred the organization of Ven2-4Cancer to a completely Belgium Foundation after setting up the event in 2009 with mainly Dutch people. Ven2-4Cancer grew and became the biggest fundraising initiative of Belgium.

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