



Inspire2Live Achievements up to now

May 11th, 2017

Inspire2Live was founded in February 2010 with the aim to empower people to convert the sense of powerlessness, caused by cancer, into one of strength. We achieve this by motivating as many people as possible to constantly challenge and expand their boundaries. Inspire2Live is founded on the absolute belief that you can attain the greatest possible satisfaction if you put your heart and soul into helping others. Our motto is "Never, ever quit!" We refuse to accept any limitations in what we can and will achieve. We have a mission:

Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer.

Achievements to be proud of.

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.

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 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.

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

Four clinical trials were chosen after being discussed by our Scientific Advisory Board. 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.

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.

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

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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.

2013.

In 2013, Inspire2Live had 6 events:

1. Alpe d'HuZes in The Netherlands,
2. The Pocho in Costa Rica,
3. Skate4Life in Norway,
4. Tour de Concorde in France,
5. Ven2-4-Cancer in Belgium and
6. 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.

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.

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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.

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.

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.

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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 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.

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 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.

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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.

Inspire2Live was already a member of European Personalized Medicine (EPEMED) and because of the cooperation with PM-Connective we are automatically a 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, 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.

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.

Other activities

Through the organization 'oPuce' we facilitate cancer patients either to stay at work or to get back to work.

Inspire2Live is involved in (inter)national organizations and journals: Member of European Cancer Concord (ECC), Member of European Personalized Medicine (EPEMED), The global Alliance for Genomics and Health, 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 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.

Our patient advocates are asked many times to speak at conferences. This is launched as an important initiative; 'If about us but 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.

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