

## Our achievements

Inpire2Live 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 and as a volunteer for Inspire2Live.

Ideas come up when an advocate discusses topics with other advocates, or when she is asked to participate in an initiative or project.

#### A number of our successes

Whole Genome Sequencing available for all patients in the Netherlands

The Dutch Parliament has unanimously approved the diagnostic method Whole Genome Sequencing for patients with metastatic cancer. For patients with Primary Tumor Unknown, the reimbursement is already included in the insurance. Other patient groups are being worked on. This is the result of lobbying by Inspire2Live.

## Fasting as part of breast cancer treatment is being researched and applied in trials

Among other researchers, Jan Hoeijmakers and Valter Longo, have made the scientific discovery that fasting weakens cancer cells. Chemotherapy becomes more effective if patients fast before starting treatment.

This is now being investigated on a wider scale and applied in breast cancer trials under the leadership of Laura van 't Veer, clinician at the University of California San Francisco (UCSF). Our Discovery Network of February 2019 in Boston has brought these scientists together.

#### Better availability of rehabilitation after cancer

Thanks to A-Care program, there is now an extensive scientific analysis and proof for the improvement of quality of life through a personalized program of physiotherapy and sports practice for cancer patients. As a result, many hospitals have set up rehabilitation programs, thereby giving patients choices that make them rehabilitate up to two times as quickly and also avoid the fatigue that is the most common long-term side effect.

This program was initiated by Inspire2Live and has a global impact for it is good, safe and cheap.

#### Introduction of fast track diagnosis

In a number of treatment centers in Netherlands, the diagnosis process has been significantly accelerated by eliminating unnecessary waiting times. Instead of waiting weeks or months 8 out of 10 people are now diagnosed within 24 hours and the other 2 within 5 working days. This reduces the period of uncertainty, stress and worry for the

## We are the patient's voice in cancer!



patient. This program has been initiated by Inspire2Live and resources and mathematic aid has been provided.

## The launch of Organoids

Organoids are mini-organs that are developed in a lab and are able to individually determine the best treatment for cancer patients by drug screening on their own tumor material. Inspire2Live successfully pushed organoids onto the bench of many cancer research labs: Cold Spring Harbour Lab, MSKCC, Sanger, to name just three. Organoids are now widely used in research which is a great step towards better clinical treatment practice and Personalized medicine.

## Magistral preparation has ended the unavailability of medicine due to costs

The high price and therefore availability of some medicines has been a topic of discussion for years. We have put the magistral preparation of medicines by the hospital's own pharmacy on the map of hospitals, pharmacy and politics (international). This has made the original medicines cheaper, which means they can now be used more easily. This is the result of lobbying by Inspire2Live. This initiative has a global impact for it is good, safe and cheap.

## Trial set-up for improved pain management for pancreatic cancer

Pancreatic cancer is one of the most painful diseases. For many years only morphine is used as a pain killer which makes it almost impossible to maintain any quality of life. Pain management in pancreatic cancer has also been a topic that received little to no attention from researchers or the pharmaceutical industry. Based on scientific research, Inspire2Live, together with the AMC, is conducting a trial with Lidocaine. Unlike morphine, this does not cause a loss of quality of life. This initiative has a global impact for it is good, safe and cheap.

## The road to excellent cancer centers in The Netherlands

We want to inform and support everyone who is directly or indirectly affected by cancer in their choice of a center for diagnostics, treatment and aftercare. A choice based on medical qualities rather than on travel distance, specializations or patient assessments.

We have started this road to excellent cancer centers by naming and discussing quality differences between hospitals and by advising patients where to go to get the best treatment for their type of cancer. We also have increased pressure on Dutch parliament to specialize and concentrate cancer care by offering a petition to the House of Representatives.

## Surgery without incision is now an option for everyone

Surgery without incision saves patients long hospitalizations and rehabilitation pathways. Inspire2Live has made it possible for patients to seek advice on their casus and getting to know whether they are eligible for surgery without incision. This way the patient can take initiative to include this method in their treatment which also increases the quality of life



for many patients. Inspire2Live has been involved in creating the website for this project and bringing together the team that looks into the cases.

# Nano-MRI has become available for early detection of metastatic urological tumors

Inspire2Live, together with the internationally well-known radiologist Professor dr. Jelle Barentsz, made it possible to detect metastatic urological tumors of 1 mm with MRI. A lifesaving acceleration of several months compared to the traditional methods where tumors were only discovered at 5 mm. With this early and precise diagnostics Inspire2Live realized an improvement in quality of care. This project started as an initiative of Professor Barentsz in a discussion with advocates from Inspire2Live.

## World Campus as a quantum leap in international cooperation

We experience that doing good for cancer patients differs in many countries but based on reciprocity we help each other. We do that in our Inspire2Live World Campus where patient advocates and scholar activists from more than 35 countries and all continents meet. Experts introduce new methods and techniques during in-depth sessions. This led, amongst other things, to joint projects on topics such as pain management, registration and analysis of cancer, optimization of cervical cancer vaccination.

In the World Campus cooperation and reciprocity is of great importance. We apply the 'Bottom-Up-Cancer-Support' (BUCS) vision and use the three 3P's:

- 1. First make sure you don't get cancer. 50% of all cancer related illnesses can be prevented. This is free of cost. **Prevention!**
- 2. Secondly: when you have cancer, make sure you live you're live the way you're used to as long as possible. This is also without cost. **Performance** = quality of life!
- 3. And finally: when you have cancer at least make sure you suffer as little **Pain** as possible. There are good, safe, and cheap medicines for treating pain in cancer (e.g., Lidocaine).