



Discovery Network Pancreatic Cancer – Belfast, November 30th and December 1st, 2017

'How to execute science in a way that it benefits patients quicker and more?' We discussed several ways of treatment (Immunotherapy, CAR-T and DC-cell therapy, Oncolytic viruses), screening, early diagnoses and using organoids for drug screening/-testing. We agreed upon the possibilities and potentials of all these and they are necessary but there is a big BUT! We have to get rid of the asymmetry of information between doctors and patients. AND we have to take care of the free transportation of patients (to an excellent cancer and research center) and drugs (towards these excellent cancer and research centers for treating and research being done with patients during their treatment). In order to achieve this, we will come up with 6 actions.

WikiPanc.

We will have a call to action in the participating countries to concentrate the patients with pancreatic cancer being treated in excellent pancreatic cancer research centers. Patients should be treated in centers that are also equipped for doing research on pancreatic cancer.

We will set up a database with data of the patients, clinicians and researchers and available techniques. It should be able to obtain feedback of all participants and grow enormously to support research better each year in order to improve treatments. It's being filled with data and maintained in these centers and meant to share with each other. By learning from other excellent cancer centers, we improve by adapting our treatments in constantly evolving trials and by learning. We create a 'learning loop' and continuously improve like the idea of Wikipedia.

Phase 2b drugs to the network.

For doing innovative research with patients we need existing drug and new and partly experimental drugs. Drugs that have passed phase 2b. For this we need 30 to 40 million to start treating patients with these new drugs. The data of the treatment will be in our network and available for everybody who joins the Network.

Market authorization is connected with reimbursement and both should be based on real live data instead of statistical data.

Write a whitepaper.

We will write a whitepaper about our initiative and have it published in the New England of Medicine. The aim is to show that there is a real need from patients, researchers and clinicians to concentrate the research and treatments of pancreatic cancer patients.

Make a movie.

We will make a movie of 2 or maybe 3 minutes to show that we need this concentration of research and treatment of pancreatic cancer patients because otherwise there is no basis for success and we will continue not to make any progress in the future.

Make a one pager.

To inform via social media, websites and informal contacts all the stakeholders in the Medical Industrial Complex we need a short statement. A kind of a Manifest.

Make a website.

A public website for the discovery pancreatic cancer network will be made with an open platform for both patients, clinicians and researchers. Patients will be informed of ongoing trials in centers participating in the network and clinicians and researchers will present their research topics and achieved results. Patients advocates will comment regularly on the progress being made by members of the network.

Participants of the Discovery Network:

Ilona Schelle (Inspire2Live), Nuria Malats (Centro Nacional Investigaciones Oncológica, Madrid), Andrew Biankin (University of Glasgow) Anton Ussi (EATRIS), Bart Colenbrander (not present at the meeting but still joining, Inspire2Live), Casper van Eijck (ErasmusMC Rotterdam, Dave Tuveson (not present at the meeting but still joining, Cold Spring Harbor Laboratories, Mark Lawler (Queen's University Belfast), Marc van de Wetering, Hubrecht Laboratories), Peter Kapitein (Inspire2Live), Ronald Brus (MyTomorrows).

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Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • www.inspire2live.org