

Availability of experimental drugs for brain tumours: bridging the translational gap

Each year, 1.100 patients in the Netherlands are diagnosed with brain tumours. The mortality from brain tumour is about as high as the number of new cases per year. Along with pancreas and lung cancers, brain tumours are among the most fatal cancers and unfortunately, nearly no progress in improving treatment or diagnosis has been made in the past decades.

Less than 10% of patients that are diagnosed with glioblastoma - the most frequently occurring primary brain tumour - are alive 5 years after initial diagnosis. In contrast to other cancer types, survival figures have not substantially improved during the last decades,. The fact that tumor biology of glioblastoma is very complex and difficult to tackle, as well as the fact that the relatively small number of patients has limited investments from pharmaceutical companies, has had their drawback on progress in the field.

Inspire2Live wants to act and not just talk. This conference is meant to increase **awareness** around brain tumours. We believe that through awareness we can put brain tumour on the research agenda better than we did so far and have the industry develop drugs that really work. But not only this; we can also activate patients to participate in research and give them the faith that we can change this deadly disease into a chronic disease like some other types of cancer already are. We have defined three topics that we will work on during the conference and for which we will take action shortly after:

1. Development and accessibility of new drugs
2. Molecular markers and clinical decision-making?
3. =1+2 How to combine new drugs and molecular markers for 'basket trials'

To make a change in the field of brain tumours that benefits patient directly, these three problems need to be addressed as a starting point. We should not accept the lack of success of brain tumours treatment. Therefore, Inspire2Live will create a platform that facilitates a discussion between patients, clinicians, scientists, industry and other stakeholders involved in this fight, to make a change that matters for patients with brain tumours today.

A one day conference will be organised in the Netherlands aiming to answer the question 'What to do for improving the results for brain tumour treatments in general and more particularly in the Netherlands?' during the Brain Tumour Awareness week on **October 28, 2015**

Practical.

The congress will be an open, one-day meeting but we specifically invite some important representatives from the brain tumour groups from the Netherlands and abroad. Essential in this conference is the knowledge and experience that we bring in from other countries. Therefore the presence of patient advocates, clinicians and researchers from other countries is most welcome.

Piarella Peralta (PA at Inspire2Live) and Jaap Reijneveld (Clinician) are the chairs of the congress.

never ever quit!



We will organize a preparation dinner the evening before the congress for our foreign guests and the organizational committee.

We kindly ask the participants to take care of their own travel and housing. For invited foreign participants we will offer reimbursement of ticket and hotel. Reimbursements will be based on economy class prices and hotels will be booked by our organization. The meeting will be hosted in **Amsterdam at De Burcht, Henri Polaklaan 9**, which offers the congress facilities for free.

In addition to the aforementioned stakeholders who will work on this challenge, we need media coverage of the congress to raise awareness with the wider public. Journalists from Dutch newspapers will be invited and most urgently asked to be present at the press conference. Our aim is to have an interview with one of the keynote speakers and a Patient Advocate on the Dutch Television. These are some examples of the attention that we want to have on the subject 'brain tumour' in general, the poor situation in the Netherlands and the possibilities that we see.

We will invite representatives of Dutch media for our press conference. Our aim is to have at least one interview with one of the keynote speakers and a Patient Advocate on the Dutch national television.

The congress will be more like a day of hard work for all the participants and we will produce a promising and ambitious plan of action at the end of the congress. Shortly after the congress we start put the plan in motion.

In order to facilitate discussion of the different topics, we will divide the participants into working groups per topic. Each working group produces minutes (with the help of students or postdocs from the AMC/VUMC) with conclusions and actions to be taken. This is done in 2 sessions. The leaders of each group work out the minutes with the students/postdocs. The chairs consolidate the minutes into a final report and plan of action. Several projects/activities will be defined based on this plan of action and will be sent to the participants shortly after the congress.

Program Board.

Roger Stupp	EORTC
Cassandra Nan	Inspire2Live
David Noske	VUmc / AMC
Jaap Reijneveld	VUmc / AMC
Peter Kapitein	Inspire2Live

never ever quit!



Program (De Burcht - Amsterdam, Henri Polaklaan 9).

8.00 Registration, coffee & tea.

- 8.20 Opening by **Wouter Bos**, chair of VUmc hospital and former vice-president of the Netherlands
- 8.30 Opening by the chairs Piarella Peralta (Inspire2Live) and Jaap Reijneveld (VUmc).
- 8.40 The contribution of Brain Tumour patients to science and patients – Eveliene Manten and Bas Dekker (Patient Advocates Inspire2Live).
- 9.00 The Basket trial initiative of the Netherlands – Sieger Leenstra (Erasmus MC Rotterdam)
- 9.20 Why are there no drugs for brain tumour patients? – Adam Cohen (Centre for Human Drug Research)
- 9.40 Why are there no drugs for brain tumour patients? – Pieter Gaillard (2-BBB)
- 10.00 The basics of development of new drugs – Roger Stupp (EORTC and Univ. of Zurich)
- 10.20 Partnering with the industry from the academic point of view - Michael Weller (EORTC and Univ. Zürich)
- 10.40 Q&A

10.50 Coffee break

- 11.20 Innovative trial designs – Susan Chang (Brain Tumor Center UCSF)
- 11.50 The value of Bio Informatics for brain tumour – Peter van der Spek (Erasmus MC Rotterdam)
- 12.10 Molecular markers – Pieter Wesseling (Radboud UMC Nijmegen/VUmc Amsterdam)
- 12.30 How to combine experimental drugs and molecular markers for 'basket trials' – Martin van den Bent (Erasmus MC Rotterdam) / Tom Würdinger (VUmc Amsterdam)
- 12.50 Q&A

13.00 Lunch

- 14.00 Working session 1. We split in 3 groups (Each group is chaired by 2 leaders).

We work out several topics during the congress in three separate groups:

Group A - Chair: David Noske (VUmc) and Huig Schipper (Inspire2Live)
How to get access to new drugs?

never ever quit!



Group B - Chair: Peter Vandertop (VUmc) and Geert Bakker (Inspire2Live)
How to integrate current molecular markers into clinical decision-making?

Group C - Chair: Jaap Reijneveld (VUmc) and Erik van Veenendaal (Inspire2Live)
How to combine new drugs and molecular markers in the smartest way for 'basket trials'?

- 15.00 Report back by the chairs of the session. In this report back the whole group gives new questions for the second session.
- 15.30 Working session 2. We split again in 3 groups (The chairs stay at their groups. The participants are different than in the first session).
- 16.30 Report back by the chairs of the session. In this report back the whole group gives the final comments to be taken into account when writing the final Manifest.
- 17.00 Wrap up by the chair.
- 17.30 Closing of the congress

never ever quit!