

# The C&I approach: resetting the pharmaceutical market.

# Cinderella & Inspire2Live Project Affordable Drugs

April 11th, 2016

## The principle

In our free market system industries are driven by maximizing profits. Pricing is determined by demand and competition, not by cost of manufacturing. The pharmaceutical industry (PI) is no exception. However, competition is minimal due to an extremely protective environment of patent and other right of exclusivity, conglomeration of the industry and complex regulation. This allows for drug prices being set as high as the expected compliance of payers, to levels that increasingly deny patient's access. The industry justifies its exorbitant drug prices by claiming high costs of development and the need to compensate for losses due to an extremely high rate of failures. This explanation carries little credibility as neither argument is supported by factual data or verified by outside financial controllers.

Adequate health care is a constitutional right in the developed world and has to be accessible to all. Many drugs are indispensable for healthcare. Accordingly, governments are responsible for the provision of effective drugs which is essentially a public function. When such functions are delegated to private industry, good governance has to balance the interest of investors with that of the public, in this case the patients. It is widely felt that the PI has lost this balance by placing profits above service to the public as its driving force,

This has not only resulted in unaffordable drug prices but also in failure to meet the need for new and more effective treatments.

We feel both these problems are aggravated by poor management resulting from loss of appropriate motivation and that they should be addressed by attempting to reset the attitude of the PI from profit driven to service driven. We believe that such refocusing will make the PI leaner and cleaner, reduce costs and time of drug development and simplify regulation. These side effects will also reduce drug prices.

## There is outside pressure needed to reset the PI

Obviously the PI is at present much too comfortable to initiate drastic changes by itself. Therefore pressure by stakeholders from outside the industry has to be campaigned for. Outside stakeholders with an interest in lower drug prices are patients, their families and the public in general, physicians, governments and in certain countries hospitals and health insurers.

## Mobilizing these parties into action is not an easy task.

Patients and doctors are held hostage by the industry not only with financial means but also by blackmail. Patients are suggested that lack of cooperation on their part may result in less efforts by the industry to furnish the drugs they need. Many physicians' careers and professional status are closely tied to clinical trials conducted and funded by the industry. Even governments are held hostage by the PI through threats to withdraw their drugs from that market and/or move out the company's local industrial activities if negotiations on pricing do not lead to an

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agreement. Moreover, governments and insurers have in common that battling high drug prices is no high priority since resulting deficits may eventually be recovered by raising taxes and premiums.

The conclusion is that the stakeholder least dependent on the PI is presently the general public in its role as consumers of health care and payers of tax and health insurance. That is not the only reason we propose the general public as the prime target for our campaign. Public pressure has proved to be a powerful instrument for bringing about drastic changes in other markets such as food, banking , textile and energy. In addition, public opinion may also exert a powerful influence indirectly as happened in the banning of mass destruction weapons by a boycott of banks involved in transactions in that area of the weapon industry.

## The outlines of the campaign.

#### Purpose.

Fair prices for pharmaceuticals. Fair being assessed as in accordance with the social responsibility of the industry: serving patients for a modest profit. Transparency to establish credibility.

#### Who campaigns?

Professional and Patient Advocate Organizations involved in the plan and others to be recruited from patient associations, disease oriented charity and health care professionals. Structure of this task force to be decided.

#### Prime target.

<u>The general public</u>, to reject current PI attitude, to demand reform. Instruments: information and education.

### Additional targets.

<u>Disease oriented charity</u>. To support patients right of access. Instruments: persuade donors to demand position statement and implementation.

<u>The medical profession</u>. To support patients right of access through affordable pricing by inclusion in clinical trial contracts.

Instruments: publications in professional journals, presentations at meetings. Reference to article 17 of Declaration of Helsinki by World Medical Association.

<u>Patients</u>. To include provision for fair pricing in clinical trial contracts in accordance with article 17 of Declaration of Helsinki.

Instruments: education.

<u>Governments</u>. To end hostage position of patients and doctors, to support and facilitate resetting PI. Instruments: discontinue protection, enforce competition, supertax unfair pricing.

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## The congress.

A one day conference will be organised in the Netherlands aiming to answer the question 'What to do to lower the prices of drugs to a social acceptable level?' The congress will be held at the Central Bank of the Netherlands **Friday April 15, 2016**.

### Practical.

The congress will be a by invitation only one day congress. We specifically invite some important representatives from the Netherlands and abroad. Essential in this conference is the knowledge and experience that we bring in from all over the world. We have to learn from everybody who is able to contribute and wants to bring back the prices of drugs to an affordable level.

Piarella Peralta (PA at Inspire2Live) and Ton Hagenbeek (Cinderella Therapeutics) are the chairs of the congress.

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 can 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 at De Nederlandsche Bank, 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.

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) 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**

- Carin Uyl Erasmus University Rotterdam
- Lou Garrison University of Washington
- Peter Kapitein Inspire2Live
- Ton Hagenbeek Cinderella Therapeutics

### Program

8.00 Registration, coffee & tea.

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- 8.15 Opening by the chairs Piarella Peralta and Ton Hagenbeek.
- 8.20 Wouter Bos (CEO VUMC, Amsterdam and former vice prime minister).
- 8.45 Lowell E. Schnipper (Chair of Cost of Cancer Care Task Force of American Society of Clinical Oncology) - A Framework for Assessing the Value of Cancer Therapies: An ASCO Initiative
- 9.10 Marcel van Raaij (Dutch Ministry of Health)
  Timely access to innovative medicines for the benefit of patients but with affordable prices. The Dutch policy perspective.
- 9.35 Lou Garrisson (Univ. of Washington) - Affordability issues in US and globally

### 10.00 Coffee break

- 10.30 Dean Baker (Center for Economic and Policy Research , Washington DC)
  Publicly Financed Clinical Trials: An Alternative to Patent Monopolies for Financing Research
- 10.55 André Knottnerus (Scientific Council for Government Policy) - Drug innovation to add societal value
- 11.20 Franco Cavalli (Oncology Institute of Southern Switzerland) - The role of the cost of drugs in the global fight against cancer
- 11.45 Carin A. Uyl-de Groot (Institute for Medical Technology Assessment, Erasmus University Rotterdam) - The truth, the whole truth and nothing but the truth about cancer drugs prices
- 12.10 Peter Kapitein (Inspire2Live)The patients perspective on the costs of drugs

### 12.30 Lunch & Networking discussions

13.30 Working Session 1. We split in 2 groups (Each group is chaired by 2 chairs )

We work out several topics during the congress in two separate groups: Group A - Chair: Lou Garrison and Ton Hagenbeek Group B - Chair: Carin Uyl and Peter Kapitein

- 15.00 Coffee / tea break
- 15.15 Working Session 2. We split again in 2 groups (The chairs stay at their groups. The participants change).

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- 16.45 Report back by the chairs of the Sessions. In this report back the whole group gives the final comments to be taken into account when writing the final Manifest.
- 17.15 Wrap up by the chairs / steps to be taken and closing of the congress.

#### **Approved Speakers (and participants)**

| Carin Uyl           | Erasmus University Rotterdam           |
|---------------------|--|
| Lou Garrison        | University of Washington, Seattle      |
| Dean Baker          | Ecoc. Center for Econ. & Pol. Res.     |
| Lowell E. Schnipper | Chair Cost of Cancer Care ASCO         |
| Wouter Bos          | VUMC                                   |
| Andre Knottnerus    | Chairman Dutch Sc. Council Gov. Policy |
| Marcel van Raaij    | Ministry of Health                     |
| Franco Cavalli      | University of Varese                   |
| Peter Kapitein      | Inspire2Live                           |
|                     |  |

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#### **Approved Participants**

Monique Kant Henriette van der Hulst Mathieu Tjoeng Gabi Rojkova Riet van der Heide Thom Duyvene de Wit Jan Cornelissen Merel Hennink Ton Hagenbeek Jan Visser **Toine Pieters** George Robillard Abidin Aliev Henri Reniers Marielle Horsting Tanja Moesbergen Piarella Peralta Nicole van Leeuwen Jan Vesseur **Ilona Schelle** 

**CZ-Health Insurance CZ-Health Insurance** Antonius Hospital Nieuwegein EHA Patient Advocate EHA EU Political Affairs Comm. HOVON Patient Advocate Cinderella therapeutics Cinderella therapeutics Cinderella therapeutics Cinderella therapeutics Inspire2Live Inspire2Live Inspire2Live Inspire2Live Inspire2Live Inspire2Live Inspire2Live Inspire2Live

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