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Dangerous liaisons: patient groups and drug companies

Increasing numbers of “partnerships” between pharmaceutical firms and patient groups are springing up throughout the world. An analysis of the situation in the United Kingdom highlights the pitfalls of these collaborations, which are distorted from the outset by clear differences in objectives and resources between the two “partners” (1).

Diverging interests. Drug companies and patient groups have their own short-term and long-term priorities, which are not as convergent as some would have us believe.

Drug companies count on patient groups to help augment their sales (particularly by recommending their products to potential clients), and to pressure governments not to adopt restrictive measures on their products. By offering patient groups a “helping hand”, drug companies are more likely to be perceived as responsible players in the health and welfare system (1).

What patient groups seek in exchange is information about their “partners” research activities and new product development, as well as information on existing treatments, financial assistance for members in difficulty, and funding for their own activities (1).

A lack of independence and transparency. Financial links between patient groups and pharmaceutical firms are not always visible. For example, a link with Roche (whose product Mabthera^o (rituximab) is indicated for the treatment of lymphomas) is mentioned in the professionals-only

section of the Lymphoma Association website, but not on the part of the site accessible to the public (a)(1).

Companies have even been known to create their own “patient groups”. For example, in 1999 Biogen created “Action for Access” in order to pressure the UK National Health Service to cover the treatment cost of interferon beta including Biogen’s Avonex^o for multiple sclerosis (1). In the United States, Eli Lilly, the company that markets the neuroleptic olanzapine (Zyprexa^o) and the antidepressant fluoxetine (Prozac^o, etc.), organised the funding of the “National Alliance for the Mentally Ill” by 18 different drug companies (1).

In Europe too. As more and more policies are decided at the international level, companies are lending financial support either to a range of related national organisations or to international federations (umbrella organisations). This is the case, for example, for two influential umbrella organisations: the International Alliance of Patients’ Organisations (IAPO, funded by a consortium of 30 companies) and the Global Alliance of Mental Illness Advocacy (GAMIAN, originally created by Novartis) (1).

Unfortunately, under the pretext of seeking “broader European representation”, some policy-makers in the Euro- ▶▶

a- A 2004 study of 68 patient groups in North America, Australia and Europe indicated that about two-thirds received funding from drug companies or manufacturers of medical equipment, but that none stated the precise level of such funding in their annual reports (ref 2).



eDITORIAL

▶ **pean Commission have chosen to address such umbrella organisations rather than *bona fide* patient and consumer organisations. It is therefore not surprising that the European Commission recommended direct-to-public advertising of prescription drugs “in response to demands from patient groups” (b)(1).**

Long live independent organisations! Patient groups play an important role in helping patients to express their needs and defend their interests. However, they are less, not more, likely to achieve these goals when they rely on the private sector for funding and information. The author of the British investigation recommends that patient groups be publicly funded, in the same way as political parties (1).

Patients, health care professionals, governments, and all persons and institutions concerned with the greater public good must be on their guard. In order to find out whether the patient groups they deal with are truly independent, we recommend asking the following simple question: whose interests does the organisation really represent? Patients, drug companies, or an ambiguous combination of the two?

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b- For further information on this subject and on the revision of the European Regulation and Directive, see the numerous articles posted on our website at www.prescrire.org.

Selected references from *Prescrire's* literature watch.

- 1- Herxheimer A “Relationships between the pharmaceutical industry and patients’ organisations” *BMJ* 2003; **326**:1208-1210.
- 2- Patient View “Health campaigners, fundraising and the growth of industry involvement” *Health and social campaigners’ News* 2004; (6): 7-62.

pETITION

24 February 2005

WHO Commission on Intellectual Property, Innovation and Health

We reprint here an international petition hosted by Consumer Project on Technology. It calls on the WHO Commission on Intellectual Property, Innovation and Health to adopt a new global treaty supporting medical research and development. *La revue Prescrire*, among other organisations, signed the petition, available at <http://www.cptech.org/workingdrafts/24feb05WHOen.pdf>

Dear Members of the Executive Board and the Commission on Intellectual Property, Innovation and Health:

The current global framework for supporting medical R&D suffers from profound flaws. A growing web of multilateral, regional, bilateral and unilateral trade agreements and policies focus nearly exclusively on measures that expand the scope and power of intellectual property rights, or reduce the effectiveness of price negotiations or controls.

These mechanisms are plainly designed to increase drug prices, as the sole mechanism to increase investments in R&D. Stronger intellectual property rights and high drug prices do create incentives to invest in medical innovation, but also impose costs, including:

1. problems of rationing and access to medicine,
2. costly, misleading and excessive marketing of products,
3. barriers to follow-on research,
4. skewing of investment toward products that offer little or no therapeutic advance over existing treatments, and
5. scant investment in treatments for the poor, basic research or public goods.

A trade framework that only relies upon high prices to bolster medical R&D investments anticipates and accepts the rationing of new medical innovations, does nothing to address the global need for public sector R&D investments, is ineffective at driving investments into important priority research projects, and when taken to extremes, is subject to a number of well-known anticompetitive practices and abuses. Policy makers need a new framework that has the flexibility to promote both innovation and access, and which is consistent with efforts to protect consumers and control costs.

To this end, a number of experts and stakeholders have proposed a new global treaty to support medical R&D. This effort has produced a working draft (the original draft in English is here <http://www.cptech.org/workingdrafts/rndtreaty4.pdf>, and there are also

translated versions in French <http://www.cptech.org/workingdrafts/rndtreaty4fr.pdf> and Spanish <http://www.cptech.org/workingdrafts/rndtreaty4es.pdf>) that illustrates a particular approach for such a treaty - one that seeks to provide the flexibility to reconcile different policy objectives, including the promotion of both innovation and access, consistent with human rights and the promotion of science in the public interest. The draft treaty provides new obligations and economic incentives to invest in priority research projects, and addresses several other important topics.

1. The World is Changing

The global trade framework for pharmaceuticals is changing. The pace of change is accelerating; the direction is toward higher prices and rationing of access, and the target of policy is often the elimination of basic government interventions to protect consumers. Most important, the world is increasingly locked in to a rigid and increasingly controversial approach to financing R&D. It is thus urgent to propose and evaluate alternative trade frameworks.

2. The Draft R&D Treaty Project

The current draft R&D treaty seeks to stimulate discussion, noting of course that the development of a treaty is a democratic process involving negotiations between member states with input from civil society. The draft treaty text is a work in progress, representing a collaborative effort with contributions from many persons over the past two years.

The discussion below concerns draft 4, and some provisions will change in later drafts. The objective of the project is to propose an international system that (1) ensures sustainable investments in medical innovation, (2) provides a fair allocation of the cost burdens of such innovation, (3) creates mechanisms to drive R&D investment into the areas of the greatest need, and (4) provides the flexibility to utilize diverse and innova-