Too close for comfort?

Drug companies have been told to publish their funding of patients' groups. **Andrew Jack** says that these groups should open their books too

When it appeared in 2002 the book *Mr Sneeze and his Allergies* seemed like any other title in the Mr Men series of children's books, apart from just two exceptions: thousands of copies were distributed free of charge with help from the charity Allergy UK to clinics; and it had two pages at the back citing Piriteze (cetirizine hydrochloride) and Piriton (chlorphenamine maleate), anti-allergy drugs made by GlaxoSmithKline.

Regulators ruled that the drug company violated the UK ban on advertising drugs directly to the general public, but the book highlighted the often subtle but powerful links between drug companies and the patients' groups that have become an important force in recent years.

Earlier this year the UK drugs regulator said it had told Eli Lilly to withdraw an information booklet for doctors that the company had written and funded but that carried only the Diabetes UK logo. Not only did the booklet fail to declare who had sponsored it: it also omitted to mention the risk for people with schizophrenia of developing diabetes when taking certain drugs, including the company's own olanzapine (Zyprexa).

And in recent months patients' lobby groups that are supported by drug companies have been at the forefront of demonstrations, letter writing campaigns, press releases, and other techniques to pressure the NHS into prescribing high profile and expensive new drugs.

Pfizer, which makes the dementia treatment donepezil hydrochloride (Aricept) and markets the inhaled form of human insulin, Exubera, gives money to the Alzheimer's Society and Diabetes UK, for instance. Roche, which makes trastuzumab (Herceptin), backs Breakthrough Breast Cancer, the Breast Cancer Campaign, and Cancerbackup.

Patients' groups are in many ways a welcome innovation in health care. They reflect the growing move towards individual empowerment in the fight against disease, and in the age of the internet they have provided clear information that was far more difficult to get in the past.

As Britain is slower than other European countries to adopt new drugs, and as some trusts fail to pay for certain drugs even when neighbouring trusts do, patients' groups can be an important lobbying force in pushing for access to and equality of treatment.

There is nothing either illegal or immoral in drug companies supporting patients' groups financially or in groups accepting it. There is an obvious shared interest and mutual sympathy, and sponsorship helps groups that often rely on volunteers and struggle to find enough funding.

But large levels of support can distort judgment and priorities. The best way to assess whether any conflicts of interest exist in the relationship is to allow people to judge for themselves. That requires a transparency that has generally been lacking.

A 2003 survey by *Which?* magazine showed that only 32 of the leading 125 patients' groups' websites listed their donors and just two explained their funding policy. A survey this year by Patient View, a specialist research group, showed that just 11% of the largest 530 patients' groups in the UK publicly stated that they received support from the drug industry, while only 2% stated the precise amount. The Alzheimer's Society is one of the few charities that makes its funding entirely explicit, showing on its website that it received £68 000 (€99 000; $124 000) from drug companies in 2002-4, which is expected to represent 0.1% of its total income.

Under growing criticism the industry has begun to respond. Last year the Association of the British Pharmaceutical Industry (ABPI), the trade body, launched a code of practice addressing relationships with patients' groups.

It stipulated that from 1 May this year companies should draw up a contract specifying the nature of any links and that they should make public on their website or in their annual report a list of all the groups they supported.

Nearly two months later the *Financial Times* (20 Jun, p 4) surveyed the large companies to see how far they complied. The information was difficult to find. Scanning the web pages or tapping "patient groups" into the sites' search engines rarely provided any easy access.

There were also widely differing levels of compliance, although most companies did provide data.

Merck published an incomplete list while awaiting approval from some groups. Novartis and AstraZeneca published no information at all online. Both initially said they believed they could wait until their first annual report after 1 May—potentially as late as spring next year. Both are now under investigation by the Association of the British Pharmaceutical Industry as a result, although AstraZeneca has since posted its list on the web.

What the data did show was the number of groups receiving support: several dozen each for Sanofi-Aventis and GlaxoSmithKline, for example.

Less clear was the depth of that funding. The association stopped short of requiring the sums involved to be made public, and so far only Eli Lilly has given an indication of the level of financial support. It says it hopes to publish the precise sums in the future.

GlaxoSmithKline, which provides a simple list of groups it supports, also says it will go further, stating, from the start of next year, the money provided and the nature of support to each group across Europe. That anticipates a code under development by the European trade body for the pharmaceutical sector and some other countries' existing codes on transparency, notably Sweden.

Provisional data from GlaxoSmithKline and Eli Lilly indicate that funding to most patients' groups is modest, amounting on average to only a few thousand pounds a year each. That hardly seems enough to subvert most groups' efforts to be independent.

But although the ABPI should consider going further and requiring levels of funding to be made public, the onus needs to shift on to patients' groups to reveal more details voluntarily.

Most groups have limited resources. But a little more effort to reflect on and demonstrate measures taken to maintain their independence could be an important internal exercise and pay considerable dividends in outsiders' perception of them. ☐

Andrew Jack *Financial Times*

MARK THOMAS

A protest organised by the Alzheimer's Society in London last week against the restriction of drugs for dementia. The charity is open about receiving money from Pfizer, which makes the dementia drug donepezil