



# Patient groups, industry support and

# medicines

**Many pharmaceutical companies provide some funding for patient groups. These voluntary health organisations seek support from a wide variety of sources. The funding they receive makes possible much important work to improve the lives of millions of people living with serious or debilitating medical conditions.**

**Pharmaceutical companies may simply donate money without reference to any specific purpose for which it is to be used. Or they may, for instance, provide funding for a patient group publication or a meeting in which they have little or no involvement.**

**In addition, patient groups and pharmaceutical companies frequently work together on industry funded projects of joint interest, such as:**

- **disease awareness programmes to help people recognise the warning signs of a condition and seek medical advice,**
- **publications about disease management and lifestyle issues or**
- **programmes and campaigns to improve the quality of health and social care of people living with specific disorders.**

**In so doing, companies work within the ABPI Code of Practice, which reflects UK and EU legislation prohibiting pharmaceutical companies from undertaking, or sponsoring, any activity deemed to be promoting a prescription-only medicine (or certain other medicines) to the public.**

**By the same token, patient groups guard their independence fiercely and think carefully about the steps they need to take to be able to assure their members and the public that this is the case.**

**Patient groups and pharmaceutical companies have constructive relationships which encourage patients to work in partnership with health care professionals in the management of their condition and towards the development of patient centred care, a key objective of the NHS.**

## WHY WORK TOGETHER?

Patient groups represent, meet the information needs of and offer support to millions of people living with ill-health. These voluntary organisations provide a crucially needed service to patients and carers, their families and the NHS.

Despite the importance of their work and the growing number of people who depend on their services, these groups are charities that have to raise money. They need to work hard to maintain and develop their funding base from a wide variety of sources such as legacies, foundations, Government and large corporations, including pharmaceutical companies.

It is natural that industry and patient groups should work together, as they have many interests in common:

- Raising disease awareness encourages people who may have a problem to seek medical advice.
- Early diagnosis and appropriate treatment of an illness can prevent or lessen the impact of long-term health problems, sparing the patient more intrusive treatment in the future and the NHS from costly interventions.
- People are more likely to follow treatment regimes that they understand and that have been chosen with an appreciation of their individual needs and life circumstances.
- People who are well-informed and able to work in partnership with health care professionals are likely to have better health outcomes, with improved quality of life.

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These are areas where patient groups are active and in which industry can work constructively with patient groups. Many companies provide some level of support, whether financial or by providing access to other company resources, for work in these areas and many patient groups actively encourage industry to contribute.

External financial support for any organisation, in whatever field, opens both parties to reasonable questions about these funding arrangements and any undue influence they might have. Pharmaceutical companies and patient groups alike are well aware that joint initiatives and sponsorship need to be thought through carefully in order to address such issues.

## ABPI CODE OF PRACTICE

Pharmaceutical companies are commercial organisations. The long and massively expensive research and development process that leads to a new medicine becoming available, and the huge financial risk this entails, could only be undertaken on a commercial basis. The success of today's medicines helps fund the research into the medicines of the future.

**In the UK, companies cannot promote prescription-only medicines to the public, and this includes patient groups. This is prohibited by UK and EU legislation which is reflected in the ABPI Code of Practice.**

**In addition, companies must take great care when they sponsor a patient group (or any third party) activity or publication, since their involvement must not lead to a breach of the ABPI Code of Practice. A sponsoring company needs to consider whether, were it to undertake that activity itself, it would be allowed under the Code.**

The ABPI Code of Practice also requires that pharmaceutical company sponsorship must be clearly and prominently displayed on any project materials, publications or meeting papers to which they have financially contributed.

## MAINTAINING INDEPENDENCE

As the Long-term Medical Conditions Alliance (LMCA), with over 100 member voluntary health groups, points out in its publication *Working with the Pharmaceutical Industry*: 'Registered charities must follow the requirements of the Charity Commission. For example, trustees of a charity have to ensure that they make the best possible use of a charity's money and assets, for the benefit of those the charity is supposed to help'.

Patient groups are highly professional organisations committed to the well-being of the people they serve. The groups are also fiercely protective of their independence, with clear priorities and plans.

Pharmaceutical companies working with patient groups recognise the limits of their involvement. Both parties should be transparent about funding arrangements, ensuring that partnership programmes and funding arrangements are not only proper, but seen to be so.

The LMCA's publication provides guidelines to enable those voluntary health organisations wishing to develop relationships with industry, to do so with confidence in their ability to maintain their independence and address reasonable concerns the public or their critics may have.

*In Working with the Pharmaceutical Industry*, the Long-term Medical Conditions Alliance states

**"LMCA believes it is important to maintain co-operative relationships with companies which develop, manufacture and market medicines and other treatments. These relationships, however, should be based on equal partnerships and developed in ways which preserve the voluntary organisation's independence."**

## CONCLUSION

Pharmaceutical companies and patient groups have important areas of common interest. As a result, many companies and patient groups have developed constructive working relationships.

**Patient groups often seek funding from pharmaceutical companies and think they should be willing to contribute. Patient groups work with industry because, and only insofar as, it meets their own objectives. As with any other sources of external funding in any area, these relationships should be transparent and financial support always acknowledged.**

The development of industry/patient group relationships should be encouraged. External funding from the pharmaceutical industry makes possible much important work carried out by patient groups for the benefit of millions of people living with medical challenges.