



# Position Paper

## Patient Support Group Collaboration with Industry

### BACKGROUND

In the support of patients and their families living with rare diseases, the work of patient groups is vital for the collection of information and establishing network links between patients, medical experts, and industry. The chief goal of any patient support group is to help the patients and families deal with their disease, and to share their experiences. It's the nature of such support groups that they represent a relatively small number of patients and that their resources are often very limited. Close association with, and support from industry is helpful and very welcome but unless managed well it can create undesirable conflicts of interest. This is reflected in recent European Union codes of conduct<sup>1</sup> defining the role of pharmaceutical industry in collaborations with patient support groups, and such groups are well advised to act carefully when accepting financial support from industry if they do not wish to compromise their charitable status.

### EXPERIENCE

The IPA has experienced an immense benefit from all of its contacts with scientific experts from within academia, clinical practice and the pharmaceutical industry. These expert contacts have been essential in our desire to explain basics of the disease, help evaluate information, to independently and separately review, verify and validate information. It is the intention of the IPA to continue to strengthen and widen all of these collaborations.

### IPA POSITION STATEMENTS

The IPA encourages a close collaboration between industry and all patient support groups, whether they are local, national or global. Because patient groups also exist to support a patient's right to treatment they have an interest in the support of companies providing treatments for their interest group. But the limited means of these groups must not be exploited by industry (see EFPIA code of practice<sup>1</sup>), and issues of transparency and confidentiality should be properly addressed. At all costs the independence of patient support groups should not be compromised; collaboration should be well-balanced, and boundaries should be defined and agreed between both parties.

In particular, when campaigning for access to therapies and medicines, patient groups should take great care not to be perceived as an extension of the manufacturing company's marketing division. This is especially difficult when a rare disease has only one therapeutic product available for which the company has marketing exclusivity. The pharmaceutical company and the patients clearly share a common interest in patient access to therapy. But the perception can be managed by being publicly transparent and by ensuring that mutually beneficial relationships are built with other pharmaceutical companies that may bring products to the market in the future.

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<sup>1</sup> European codes of Practice: [www.efpia.org](http://www.efpia.org). Search for "National Codes"

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