

Working with Pharma: An Example from the UK

1. There are 3 UK trade associations but the **ABPI** (Association British Pharmaceutical Industries) is favoured by government as a '**negotiating partner**'.

ABPI member's relationships with Patient organisations are governed by a '**Code of Practice**'

2. **The ABPI 'Code'** has 25 Chapters, only one of which covers relationships with patient organisations.

Industry has many other relationships with for instance, medical profession, media and other organisations, including government.

The Code covers these as well as other areas such as marketing authorisation

The Code is administered by an independent dedicated body called **PMPCA** (Prescription Medicines Code of Practice Authority)

3. The Code also covers non-financial (in kind) aspects of their member's relationships with patient organisations e.g. the use of a patient organisation's logo, hospitality for carers and provision of information, **BUT**

Public and press attention is always focused on the financial support that ABPI members (Pharma Companies) give to patient organisations.

Clause 23.7 requires **ABPI members** to disclose details of patient organisations they give support to, identifying specific activities as well as the total financial support granted in any one year. This information needs to be publicly disclosed by the end of the first quarter following the end of the previous year. For example, for 2012 details must be publicly available by 31st March 2013

The information covering industry support that the CML Support Group and other UK groups received for 2012 is published on the UK websites of Novartis, BMS and Pfizer.

4. Why should the Pharma Industry support patient organisations?

Why not?

- It fulfills part of their corporate social responsibility duty, as they do with other projects e.g. the Pfizer UK Foundation which runs prevention projects.
- For small patient run groups, fundraising costs money when carried out on a larger scale
- CML is rare so it is difficult to compete with more common cancers/diseases.
- It is more difficult to raise funds for rare cancers because the general public is not as aware of rare diseases, particularly those that generally affect older patient populations.

5: Top tips

1. Develop specific 'Projects' rather than ask for general unrestricted grants.

*Include operational (running) costs within project costs

2. Don't just have a 'general vision' – be specific about your aims and think carefully about what service you want to offer your members. Set out clear objectives within realistic timelines.

Remember: There is more than just 'one model' in the 21st century.

3. Patient Groups are always 'a work in progress', so continue to improve and update the service you provide, but always within your own and your group's capabilities.

As the world changes you should change with it

4. There will always be critics: people and organisations with an 'agenda' will remain critical of patient groups. Learn how to deal with this as '**a fact of life**'.

Try to understand what the criticisms are based on; you can then confidently counter them. Have confidence and a clear idea of what you are doing so you can always be well prepared to defend your actions.

- Asking for financial support from industry does not mean that you are compromised or that you have to agree on every issue.
- Many other interest groups accept support from industry, including the medical/research profession/academics etc.
- Create transparent as well as constructive relationships
- Be clear and honest with the companies that are willing to support you
- Always maintain and express your independence
- Make sure you are never in the position of being perceived as a 'mouthpiece' for anyone other than your members, be that industry, medical organisations, other interested groups or governments bodies.
- Patient Groups and Industries interests will often converge and align well,

But not always!

Encourage industry partners to see this as a good thing! Having clear water between you maintains everyone's credibility, especially yours.

5. Above all, value and guard your independence

Notes:

UK Trade Associations:

- 1. Association of British Pharmaceutical Industries (ABPI)** Major industry association and favoured government representative bod. Every Big Pharma is a member excepting Roche
- 2. Bio Industry Association (BIA)** biotechnology focused, close relationship and shared offices with the ABPI.
- 3. Ethical Medicines Industry Group (EMIG)** for pharmaceutical SMEs especially those with a focus on inherited conditions & rare diseases.

ABPI Code - section covering financial support to patient groups

Clause 23.7:

Each company must make publicly available, at a national or European level, a list of patient organisations to which it provides financial support and/or significant indirect/non-financial support, which must include a description of the nature of the support that is sufficiently complete to enable the average reader to form and understanding of the significance of the support. The list of organisations being given support must be updated at least once a year. The published information must include the monetary value of financial support and of invoiced costs. For significant non-financial support that cannot be assigned a meaningful monetary value, the published information must describe clearly the non-monetary value that the organisation receives.

Clause 23.7: Date of Implementation:

A list of patient organisations including the monetary value of support regardless of its level must be made publicly available by the end of the first quarter of 2013 and cover activities commenced on or after 1 January 2012 or ongoing on that date. Until that information is made publicly available, the requirements for disclosure set out in Clause 23.7 of the 2011 Code of Practice and its supplementary information remain applicable.



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