

EPDA guide to

Working with the treatment industry



EPDA GUIDE TO... WORKING WITH THE TREATMENT INDUSTRY

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INTRODUCTION

The EPDA has worked with the treatment industry for many years now and, thanks to their support, we have been able to develop many projects that have in turn benefitted our member organisations. It's important to remember that your national treatment companies may also be able to provide your organisation with valuable support to help project development and to raise awareness of Parkinson's.

The treatment industry can assist in many ways – from providing funding and assisting with the development of educational materials to organising event logistics and campaign launches. However, be warned: ethical and transparent relationships are vital, and to make all of our lives easier a simple code of practice has been developed by the European Federation of Pharmaceutical Industries and Associations (EFPIA) to explain how your relationship with the treatment industry should work (see page xx).

We hope that this document will give you the confidence to develop positive working relationships with the treatment industry. Never forget that the EPDA is available at all times to provide advice on developing partnerships with the treatment industry. If you have any questions at all, please email info@epda.eu.com.



Knut-Johan Onarheim
EPDA President

SECTION 1 INDEPENDENCE THROUGH SHARED GOALS

Working with treatment companies can greatly strengthen patient organisations' campaigns, whatever they may be. When relationships are strong and transparent you can join forces and share resources in order to get shared messages across.

Relationships with the treatment industry can and should be based on open and honest partnership. Not only can the treatment industry provide funding for a range of initiatives but they can also work with you on policy development and practical initiatives.

Independence is a key point: treatment companies make a point of keeping theirs – and so should you. However, patient organisations should also recognise that there will always be differences in opinion and vision. For example, something that will never change is the fact that treatment companies will always strive to be profitable – they are, after all, first and foremost, businesses.

They will also have their own particular marketing agendas that they will adhere to. However, no patient organisation should ever feel obliged to conform to these agendas. Funding should always be rejected if the alternative is compromising your independence in any way. You must also remember that advertising of any prescription medicine to the public is not allowed in the EU.

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Ensure that you provide the treatment industry with a copy of your organisation's policy for working with the industry – and if you don't have one already established, prioritise it immediately. It is also good practice to minute all meetings and actions agreed in addition to having specific agreements and team leaders in place for individual initiatives or programmes.

SECTION 2 DEALING WITH THE CORPORATE STRUCTURE

OBTAINING INTEREST, ASSISTANCE AND, FINALLY, GRANTS

Before you contact a treatment company to gauge their interest in a project, it is important to understand their business structure. Larger companies are likely to have different offices that cover different regions of the world, as well as national-level offices. A good point of contact will usually be the national office situated within your country.

Some companies have schemes that are specially designed to fund not-for-profit organisations, which you can use to apply for funding. These grants are ideally 'unrestricted educational grants', which means you are free to use the funding without conditions imposed by the company. However, funding is likely to be provided for educational purposes only (such as disease awareness campaigns), rather than for the running costs of your organisation or equipment.

Most companies have separate medical and marketing departments, while others have specialist personnel responsible for communications and relationships with advocacy groups. If no specific funding scheme is available, try to speak to someone from the marketing department or the medical representative in your

country. If you are looking for logistical or other support rather than funding, make this clear in your initial conversation.

It is a good idea to approach more than one treatment company to fund a project. This will show that you are not associated with an individual company or product. No company can demand that it is the sole funder of an organisation or major programme.

APPROVAL PROCESSES

If a treatment company agrees to fund or support your materials or campaign, all relevant documents (including contracts) will have to be approved by them. This approval is needed to ensure the accuracy of statements and to check that any materials do not break the treatment industry's funding rules. However, the treatment company should not attempt to influence the content of materials to suit their commercial needs. You retain final sign off on all activities.

Make sure that you leave enough time for their medical and legal departments to approve materials. This can take several weeks, so plan your work carefully.

SECTION 3 TRANSPARENCY AND CODES OF PRACTICE

EFPIA CODE OF PRACTICE

In an attempt to make the funding process smoother and more trusting, the European Federation of Pharmaceutical Industries and Associations (EFPIA) has produced a Code of Practice on relationships between the treatment industry and patient organisations. It is essential that all treatment companies within Europe adhere to this code – as well as any other respective national codes of conduct that apply elsewhere.

The Code of Practice is available from the 'Publications' section of the EFPIA website: www.efpia.org. In addition, look out for the EFPIA's logo as a sign of accreditation.



DECLARING COMMERCIAL SUPPORT AND SPONSORSHIP

You must declare commercial support and sponsorship on all materials. Transparency is key to this process – not only for your organisation but also for the treatment company as well as governments and other associations around the world.

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Trust is vital, and you must discuss with the treatment company how they would like to be recognised, which includes the use of logos. You should also add statements declaring funding. For example, “This article has been funded by an unrestricted educational grant from...” or “Logistical support for this meeting has been provided by...”. Conversely, if a treatment company wishes to use your logo or materials, they must obtain your written permission to do so.

CONCERNING CONTRACTS OR LETTERS OF AGREEMENT

Patient organisations and the treatment industry must have a written agreement that sets out exactly what has been agreed between the two (or more) parties, including details of support and funding for every activity or ongoing relationship. An example contract can be found in Annex 1 of the EFPIA code.

NATIONAL CODES OF CONDUCT

In addition to the EFPIA code, there could be a local code set up by your national treatment industry organisation. If so, ensure that you familiarise yourself with this code. Links to national codes can be found through the EFPIA. See www.efpia.eu/Content/Default.aspx?PageID=579.

SECTION 4 EXAMPLES OF SOME SUCCESSFUL PROJECTS

There are a number of useful resources and occasions that you can take advantage of when working in partnership with treatment companies. For example:

SALES AND MARKETING

Distribution by sales force representatives. Treatment companies' typically have at their disposal extensive and well-trained sales forces that can deliver your materials to local physicians across Europe to highlight disease education and advocacy support.

Meetings and congresses. You could distribute materials from treatment company exhibition stands at appropriate national medical congresses.

Speaking opportunities. The treatment company could give you a platform at relevant meetings for physicians to inform them of your organisation's work.

THE EPDA

The EPDA is a good example of how to work with the treatment industry. In recent years it has secured industry support for the majority of its projects – including the Life with Parkinson's awareness campaign (www.parkinsonsawareness.eu.com), **xxxxxx and xxxxxxxx (anything else to add?)**. We are naturally very grateful for all

this support – both financial and otherwise – without which we could not carry out our work programme.

Take Life with Parkinson's as an example. The awareness-raising campaign was supported by a number of companies – all of which are clearly recognised on the acknowledgements page of the campaign booklet and the website. In addition, Teva and Lundbeck have supported a number of other EPDA activities throughout the years, including:

- The translation of the Life with Parkinson's campaign materials into multiple languages
- The commissioning of a survey that assesses the knowledge of Parkinson's among the general public across Europe. The data that was generated was used to make the launch of the campaign compelling to journalists
- The dissemination of EPDA educational materials to healthcare professionals through their stands at medical congresses.

USING PATIENT CASE STUDIES

Treatment companies might approach you for patient case studies, which they sometimes use in their promotional and educational materials. Everything that the company states – or the patient states – about the disease/response to treatment will be subject to the specific treatment industry regulations in your country.

The chosen people with Parkinson's must be typical in terms of their condition and response to therapy. For example, those at the severe end of the disease spectrum or with an outstanding response to treatment should not be selected. People can be compensated if they give up a

significant amount of their own time to provide case study material to a company (such payments should fairly reflect the time and effort involved). However, if the person was sourced directly from the patient organisation, then the payment should be made to the organisation and not to the individual.

In certain cases, treatment companies might want to put people in touch with the media. Consumer publications often like to tell a story from a person's perspective so their readers will identify with the story more strongly. If the treatment company wishes to do this, make sure that the person is happy to be interviewed before agreeing, and support them throughout the process.

As part of the Life with Parkinson's media campaign, Teva and Lundbeck filmed the EPDA, healthcare professionals and people with Parkinson's sharing their experiences of diagnosis, treatment and living with the disease. The films were made available to digital media through a multimedia press release (www.oursocialmedia.com/uk/epda-uk/life-with-parkinsons), which subsequently boosted online coverage of the campaign launch, while high-quality footage was made available to broadcast media.

DIGITAL IDEAS

Treatment companies could also support you in developing online components of your campaign. For example, you could work with a local treatment company to produce case study films to support your campaign, or they could help create a clever 'viral' video about the campaign that members of the public will want to send to their friends. This can help increase the campaign's reach with minimal cost.

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SECTION 5 SHARE YOUR SUCCESS

It is essential to let the EPDA know what you are doing and the results you are achieving so we can all share these great ideas and successes with other member organisations across Europe. The EPDA has several forums – including traditional print and online media as well as the ever-popular social networking sites – that can be used to highlight and showcase the work that you have been doing. For example:

- *EPDA Plus* magazine, which is now available in five languages and published three times a year. It boasts a global readership and you can download current and previous issues at www.epda.eu.com/epda-publications/epda-plus/download.
- EPDA YouTube channel, which showcases Parkinson's-specific video content. It is growing rapidly so go to www.youtube.com/user/theEPDA and check it out.
- EPDA Update, the e-newsletter that reports on the world of Parkinson's every other month. Visit [xxxxxxx](mailto:info@epda.eu.com) to see previous issues and email info@epda.eu.com to get onto the mailing list.
- social media: the EPDA is now on Facebook (www.facebook.com/theEPDA) and Twitter (EPDA@euparkinsons). Get online and get involved!
- you should also check out the EPDA's Life with Parkinson's awareness campaign at www.parkinsonsawareness.eu.com.

CASE STUDIES

The following two case studies are examples of what can be achieved when EPDA member organisations work with the treatment industry.

1. EPIKOUROS - kinisis

The Greek member organisation launched a photography contest via Facebook and held a conference to celebrate the European Parkinson's Action Day on 17 April 2010. The purpose of the two events was to raise awareness about Parkinson's in Greece, and it achieved this through the holding of a press conference and the production of a 30-second television advert that was aired across the country.

The results were extremely encouraging: the awareness of Parkinson's was significantly increased throughout the country, while the organisation's membership rose from 300 to 800 following the campaign.

2. Federación Española de Párkinson's

The Spanish organisation drove awareness of Parkinson's – and at the same time celebrated World Parkinson's Day – by launching the "Come on everybody. Let's move!" campaign in April 2010.

Activities included a press conference and a Spanish television news bulletin that promoted the EPDA's Life with Parkinson's awareness campaign DVD.

The organisation also set up www.parkinsonpresson.org, a network similar to Facebook and Twitter, where people with Parkinson's, their families and health professionals can participate and keep in touch on a regular basis.



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