

How the EPDA can assist companies raising awareness about clinical trials

Overview

As the only European Parkinson's umbrella organisation, the European Parkinson's Disease Association (EPDA) often receives requests for partnership from companies working on **clinical trials** of new Parkinson's medicines and treatment/management devices.

Although the EPDA's work programme has not traditionally directly focused on scientific/medical research, our [strategic goals](#) do include **supporting the global Parkinson's community in the search for a cure**. In order to fulfil this goal, we are looking at new ways to raise awareness of the research opportunities that are available to people with Parkinson's and their families – which include clinical trials.

Preliminary questions

The first step of any potential collaboration between the EPDA and a company/institution involved in the running of clinical trials would be for the company/institution to provide us with some **preliminary information**, as detailed by the following questions:

- What is your company/institution's **primary objective** in relation to working with the EPDA?
- At what **stage** is your clinical trial process – I, II or III?
- Is your clinical trial listed on any of the most common **trial portals** (eg, [Fox Trial Finder](#))? These portals are used by people to find relevant trials in which they can participate. See for information our page about [clinical trials](#).
- What **countries** are participating in the trial?
- Does your company/institution have affiliates in the countries where the trial is taking place?

If your company/institution does not have affiliates, does it have **study coordinators**? If so, would it be appropriate for a national patient organisation to communicate directly with the study coordinator in the country?

In addition to the above questions, we will ask you to provide us with any other relevant details regarding the trial. In particular, we will ask you to supply the trial **informed patient consent form**, and to confirm that the form has been endorsed by an ethical committee.

Please note that under the new [EU Clinical Trials Regulation](#), it will be your company/institution's responsibility to submit copies of information materials – including the start and end date of the trial – to all **relevant authorities** (medicine agencies and/or other regulatory bodies) in the country/countries where the trial is taking place.

How we can work together

Due to the EPDA's **independence and transparency rules**, as detailed in our [code of practice](#), it is **not possible** for us to:

- actively attempt to recruit patients for a clinical trial carried out by a private company or research institution
- actively advertise any specific clinical trial carried out by a private company or research institution
- endorse any product developed by a private company in any way.

We are instead able and willing to **raise awareness about the importance of the patient community getting involved in the clinical trial process** – which can indirectly lead to patient recruitment for a company/research institution-led trial.

If companies are interested in working with the EPDA to educating and raising awareness about the clinical trial process, this can be carried out along one (or both) the following options:

Option 1 – Introduction of the clinical trial(s) to the EPDA's member organisations (national European Parkinson's associations) in the relevant countries

The EPDA strongly recommends that companies working on clinical trials in different countries make contact with **national Parkinson's organisations** in each of the countries where the trial is taking place. We consider this to be a very important priority (not to mention an important act of courtesy), and it is also where the EPDA, as a European Parkinson's umbrella organisation, would be able to help you the most.

Using direct communication channels, we can contact the **EPDA's [member organisations](#)** and advise them about the availability of the trial in their countries.

In these instances, your company/institution will have to provide us with the following:

- information about the trial – translated into the **local language**
- the **informed consent form** used for all patients – an English version and one translated into the local language
- details of a **contact** in the country (either an affiliate or a study coordinator)

Following any introductions made by the EPDA, it will subsequently be the responsibility of the national patient organisation (the EPDA member organisation) to contact their own members and networks and share the information about the clinical trial. **It will not be possible for the EPDA to control the outcomes of this process.**

From this point onwards, the EPDA recommends that the national Parkinson's organisation and the in-country contact person from your company/institution (affiliate or trial coordinator) establish an **ongoing relationship** (to ensure the EPDA member organisation understands and supports the clinical trial) as well as a process on how to proceed.

Please note that, even if the national patient organisation in a certain country is not a member of the EPDA, in some cases it will still be possible for us to try to make an introduction.

Please note that the EPDA would kindly expect a donation from your company to compensate for our time spent working on this option.

Option 2 – Parkinson’s Life sponsored article and targeted social media/paid advertising

This option would allow the information and awareness-raising about the issue of clinical trials (and their recruitment) to reach a different readership via the **EPDA’s online magazine [Parkinson’s Life](#)**. There is also the possibility to target specific countries.

For your company/institution to publish a **sponsored article** on Parkinson’s Life, you will have to:

- adhere to Parkinson’s Life’s [sponsored article guidelines](#)
- ensure the article is **neutral and informative** and does not include any wording that could lead to unrealistic expectations
- ensure the article is aimed at providing **valuable information** to the Parkinson’s community and **raising awareness about the importance of clinical trials in general**, rather than being focused on promoting your company’s specific trial
- ensure the article **is not actively aimed at recruiting patients** to any specific trial
- ensure the article meets your company’s own **internal regulatory compliance**.

Please find below, as an example, links to sponsored articles that, being compliant to our guidelines and policy, have been published on Parkinson’s Life:

- [STEP – The lived experience of Parkinson’s disease](#)
- [How state-of-the-art tech allows DBS upgrades without extra head surgery](#)
- [How Parkinson’s wearables can deliver accurate data from patient to neurologist](#)

If your company/institution adheres to the above guidelines and proceeds with the sponsored article, the EPDA (via Parkinson’s Life) can offer some **‘bolt-on’ optional extras** that come as a result of paying for a sponsored Parkinson’s Life article. These extras would represent the most beneficial option for your company/institution in terms of **targeted reach**, but it will come at an additional cost. The optional extras include:

- **social media content creation and scheduling/posting:** as a bolt-on to already created sponsored articles, social media content can be created, scheduled and posted by the Parkinson’s Life team at specified times for specific target markets. Activity will be spread over a week, starting on the day of the article’s publication.
- **paid promotion:** as an extension of the social media content creation and scheduling/posting option, the Parkinson’s Life team can manage a paid advertising/promotion campaign, using the social content already created (selecting one or more posts created above). The campaign would be based on pay-per-click in Facebook or other target channels.

More information

Please contact the EPDA’s Natalie Levenhagen (natalie@epda.eu.com) for more information about this process.