The Migraine Trust’s policy on working with industry, corporates and funders

Overview

The sole purpose of The Migraine Trust is to improve the lives of people affected by migraine. Our three strategic goals are as follows:

1. Help find a cure – play a major role in encouraging new research and treatment to alleviate the symptoms and impairment caused by migraine and ultimately to find a cure.

2. Ensure every single person with migraine – no matter who they are or where they come from – gets an accurate, timely diagnosis and access to the best possible information, care and treatment and has the same legal protections as other disabled people.

3. Build an active and supportive community of people affected by migraine (PABM) – this community would act as both a source of support and a movement for change.

We also have a series of organisational values that guide all our decisions and actions. We expect everyone who works or represents us – including our trustees and volunteers – to model and champion these values in their day-to-day activities:

1. **Integrity** – we are trustworthy, transparent, honest and impartial
2. **Inspiring** – we make things happen, we are forward thinking and are leaders in our field
3. **Knowledgeable** – we use and share evidence and up to date research findings
4. **Listen** – everything we do is based on the experiences of people affected by migraine
5. **Ambitious** – we are committed and demand better
6. **Community** – we bring the migraine community together

Everything we do must help us further our three strategic goals and all activity must reflect our organisational values.

We are completely reliant on maintaining the trust of the people who need our help and those who support us

We are acutely aware that our charity is completely reliant for our continued existence on maintaining the trust of people affected by migraine, our supporters, people working to support people affected by migraine in the NHS, the research community, the Charity Commission, and the wider public. It is a responsibility we take extremely seriously.

When we talk about ‘industry’, ‘corporates’ and ‘funders’ we mean the following:

- **Industry** = any company working in the field of health or disability. In practice this usually means a company working in the health and migraine field, e.g. a pharmaceutical or medical device company.

- **Corporates** = any private company.

- **Funders** = a government department; non-government agency (e.g. NHS England); a think tank; a charitable trust or foundation; or an individual donor giving The Migraine Trust funding.
Working with industry, corporates and funders can present fantastic opportunities to further our three strategic goals and improve the lives of people affected by migraine.

But if we are not entirely open and transparent about these relationships, or we don’t have clear rules in place, there is a risk that people may perceive that these groups have undue influence over the decisions our charity makes.

In saying this we need to stress that industry, corporates and funders generally do not donate to The Migraine Trust in order to try to unduly influence our agenda. Industry and corporate partners are as acutely aware as we are that their existence is dependent on trust, they have their own values against which they want and expect to be judged, and they must abide by their own industry codes of conduct. However, it is sensible for all parties to have in place a clear set of rules and ways of working that prevent both undue influence, and the risk of the perception of undue influence.

Key principles for working with industry, corporates and funders

Alongside our strategic goals and organisational values, below are some rules and principles about how we work with industry, corporates and funders:

1. **Being open and transparent**
   - We will publish this policy on our website and refer to it in our annual report.
   - We will publish the names and amounts of all donations given by industry and corporate partners on our website and in our annual report. We will also set out what the money was given to do.
   - When an industry or corporate partner gives us a new donation, we will expect them to sign a written agreement making clear that they actively support – and will seek to uphold – our industry, corporates and funders policy.
   - We will be open and transparent about who has been involved in the development of our policy influencing and research agendas and how these policies were developed and pursued.
   - We will publish the names of anyone who has provided financial or other material support in the development of any content we publish, e.g. information leaflets, films, policy reports, strategies etc, as part of the content.
   - We will be open and transparent about our staff and trustee relationships with industry and corporate partners, publishing these on our website and in our annual report. We will also seek declarations of interest at Board meetings and ensure any trustee with a conflict of interest – or a perceived conflict of interest – does not take part in any decision-making related to that conflict of interest.
   - We will be open and transparent in response to any public or media enquiry regarding our work with industry and corporate partners or any funder.

2. **An Ethics Committee to support and review issues and policies**

While The Migraine Trust Board retains overall responsibility for all charity issues, we have a nominated group of trustees who have been given delegated authority to review and propose updates to this policy on an annual basis,
check that it is being implemented effectively, approve in advance any donation by industry, corporates or funders of more than 10% of our total annual expenditure (approximately £70k in 2019-20), and to act as an arbiter for any questions or issues that arise in the day-to-day operation of this policy.

3. Meeting Charity Commission guidance and GDPR requirements

- We will work to Charity Commission guidance when working with industry and corporate partners and funders.
- We will work to all requirements under the General Data Protection Regulations (GDPR).

4. Assuming the best intentions of our industry and corporate partners

We think our industry and corporate partners want to do the right thing. It is in their best interests to do so. As part of this commitment, as well as this policy we expect them to meet their own codes of conduct at all times. For example, pharmaceutical companies must meet the ABPI code of conduct and are actively encouraged to follow the ABPI sourcebook when working with patient organisations.

5. Working to deliver our three strategic goals as articulated in our organisational strategy

- We will only undertake activities that seek to deliver our three strategic goals as articulated in our strategy. Our strategy is approved on an annual basis by our Board. We will be open and transparent about how our strategy has been developed and who has been involved in its development. All new programmes of work outside of this annual strategy will require Board approval.
- If an industry or corporate partner gives us funding to support a specific project within our strategy, a clear written agreement for that project will be drawn up, monitored on a regular basis, and evaluated. We will provide the partner with regular updates on progress in the delivery of the project. We expect this written agreement to include clear project objectives and a timeline for all activity and for it be clear how this project helps to deliver our three strategic goals and our organisational strategy.
- While we are happy to consider funding for specific pieces of new migraine research from others, and to fund specific pieces of new research in partnership with others, we will only fund new research that has been approved by our Scientific Research Committee (SRC). The SRC will only approve funding for new migraine research which it feels will help us to deliver our three strategic goals as articulated in our strategy. The SRC’s recommendation also needs to be confirmed by our Board.

6. Being independent and evidence-based

- We will actively encourage industry, corporates and funders to give us donations that are unrestricted, i.e. the funding they give us can be used however we see fit. We think this is the best way for us to further our strategic goals while at the same time avoiding any perception of undue influence over our activities.
- The Migraine Trust will only accept financial or other material support as long as funding is provided free from any conditions that might compromise – or might be perceived as compromising – our charitable status, independence or reputation.
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• Where funding from industry and corporate partners or a major donor is sought or given for a specific project, we will actively seek to encourage as many industry or corporate partners or major donors as possible to support that project to reduce the perception of undue influence over how the project is run or what it delivers.

• The Migraine Trust will always have complete editorial control over the content of all plans, policies, written outputs, agendas and meetings, etc.

• All staff, Board members, volunteers and anyone outside of our organisation producing content on our behalf (e.g. an article for Migraine News or our monthly e-bulletin) are required to complete a declaration of interests form. Any conflicts of interest, or perceptions of a conflict of interest, will be reviewed by our Ethics Committee. Anyone found to have acted not in accordance with this policy, our values or to have not acted in the best interests of our charity will be dealt with through our disciplinary procedures.

• We will not actively endorse or promote specific products, treatments or services by individual companies or other parties unless we are working in partnership with them. If we are working in partnership with them we will be clear, open and transparent about that relationship and it will be clear that the partnership is to further our three strategic goals.

• When talking in public about any products, treatments or services provided by others that may be of interest to people affected by migraine, NHS professionals or others, we will give an honest, objective opinion, based on published evidence wherever possible and appropriate, and always from the point of view of what we believe to be in the best interests of people affected by migraine. This includes any products, treatments or services provided by individual companies or other parties who we are working in partnership with.

• On our website we maintain a public database of clinical trials that are recruiting volunteers. We seek approval from our Scientific Research Committee before we publish these opportunities on our website. We do this for the purposes of informing people affected by migraine and to support the advancement of migraine research. However, we are clear that we are not in a position to recommend a clinical trial and we receive no payment from any party for providing this service.

• Our name and / or logo are our property and must not be used by anyone without prior written agreement.

• We will never lobby or campaign for an industry or corporate partner or a funder’s interests. We are happy to work alongside them where their interests align with ours (as articulated in our strategy). For example, we would be comfortable making the case for a particular drug treatment to be made available to (a group of) migraine patients on the NHS if and where we felt it was in their best interests to have access to that drug treatment.

7. Acting ethically

The Migraine Trust will not accept money or support from any party whose activities or business practices we perceive to cause harm to health and wellbeing, to be damaging to the public good, or to be unethical. We will undertake our own due diligence on all potential industry and corporate partners. If we discover subsequently that we have accepted funding from any party who we believe does not meet our ethical standards, we will give the money back as soon as possible and declare we have done so on our website and in our annual report.

We also do our best to ensure that any investments we make are not in companies that we perceive to cause harm to health and wellbeing, to damage the public good, or to be unethical.
8. Taking additional care with large donations

Our Ethics Committee will approve in advance any donation by an industry or corporate partner or funder of more than 10% of our total annual expenditure (approximately £70k in 2019-20).

9. Our fundraising strategy for the next 10 years

Our policy on working with industry, corporates and funders needs to be viewed alongside our wider fundraising strategy. Over the next decade we will seek to significantly grow our donor base. We would like to encourage as many people affected by migraine as possible to invest in our charity so that we can do more to help improve more lives. We also think that the broader our fundraising base, the more financially sustainable we are as a charity, and the more financial independence it gives us.