

Policy on working with the medicines industry

Background

Collaborations between medical research charities and the medicines industry can deliver significant benefits for patients and wider society, by:

- Helping industry partners to understand what matters most for patients and their families;
- Speeding up the development of new treatments and therapies;
- Improving how existing treatments and therapies are used to improve health and quality of life.

Policy Aims and Objectives

This policy sets out clear principles and guidance for how the Tuberous Sclerosis Association (TSA) works with the medicines industry.

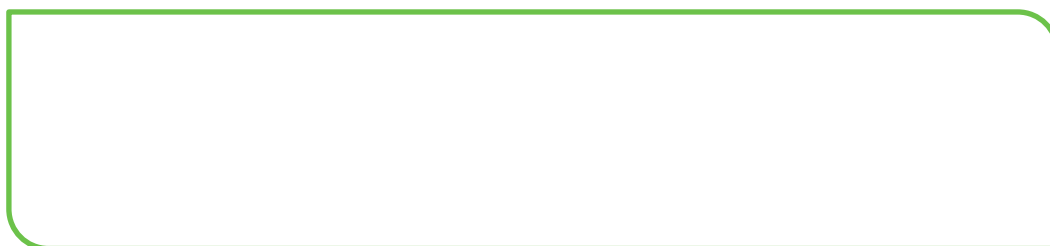
Fit with the TSA's charitable objectives

We will only seek and accept support from industry partners for projects that help us to deliver our charitable objectives. These are:

- To support individuals affected by TSC, together with their families or carers
- To encourage and support research into the causes and management of TSC
- To provide education and information for individuals, families and the health, social care and education professionals who support them.

Openness and transparency

The TSA is a member of the Association of Medical Research Charities (AMRC), and we will apply working with industry principles in line with the AMRC recommendations of independence, integrity and transparency.





The pharmaceutical industry is bound by the Association of British Pharmaceutical Industry (ABPI) Code of Practice, and we will make sure that any funding or joint activity undertaken by the TSA will comply with the conditions set out in the Code of Practice. In particular, we will be mindful of Clause 27 of the Code of Practice on Relationships with Patient Organisations.

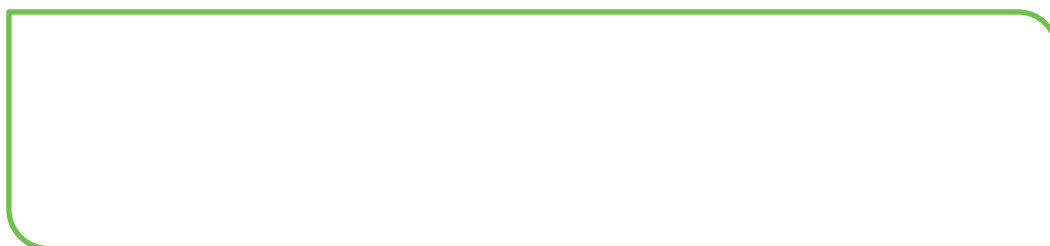
Principles

We will adhere to the following principles when working with pharmaceutical firms:

1. When we work with the medicines industry, it will be because we believe that this will bring benefit to people who are living with TSC and those who care for them.
2. We will only work with the medicines industry when it does not affect our independence, so that we are free to comment both positively and negatively about pharmaceutical companies and their products.
3. We will make editorial decisions about the information we publish for people living with TSC, families and professionals based on the latest evidence and informed by the views of our patient community and expert clinical advisers. Our editorial decisions will never be influenced by the acceptance of funding or support from pharmaceutical companies.
4. We sometimes campaign for equitable access across the UK to a particular drug or treatment. We will not accept funding from pharmaceutical companies (whether they are drug developers, manufacturers or competitors) to support our campaigning activities where they relate to a particular drug or treatment.
5. We will not accept support from any company that is attempting to influence the charity's policy or information materials, or attempting to influence policy-makers for commercial advantage through association with the charity.
6. We will not work with an industry partner when it may damage our reputation, and we will terminate any relationship that becomes a threat to our reputation.

How we work with the medicines industry

There are a number of ways that we work with the medicines industry, including:



Providing advice on the design of research and trials: We work with industry partners by commenting on the design of research and trials to ensure that they are constructed in a way that collects data on what matters most for patients and carers, and makes it as easy as possible for individual patients and carers to take part in it.

Supporting patient and public involvement in research and trials: We raise awareness among patients, carers and NHS TSC clinic leads when new research or a new trial is being set up by an industry partner, so they can make an informed decision about whether they want to find out more about the trial and take part in it.

Advisory Boards and working groups: We will participate in advisory boards and working groups to help an industry partner to better understand what matters most to people living with TSC and their families.

Sponsorship and exhibition opportunities at events: We accept sponsorship and provide exhibition opportunities at our research conferences and clinic days to help us fund these events and drive forward the TSC research agenda. Event sponsors have their brand recognised as a sponsor and may attend as delegates, but have no influence over the programme or organisation of the event. If we offer an opportunity to deliver an industry-sponsored symposium session, we will be clear and transparent that the session is organised and delivered by a named pharmaceutical company.

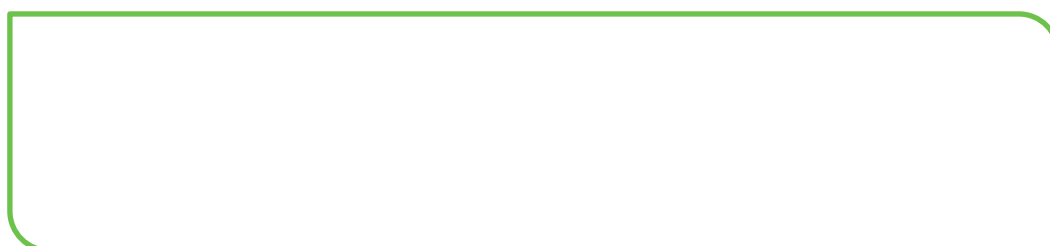
Unrestricted educational grants: We apply for unrestricted educational grants from pharmaceutical companies to fund our broader work supporting individuals living with TSC and their families, and providing information for individuals, families, and the health, social care and educational professionals who work with them.

Processes

We will publish a full breakdown of the funding received from the medicines industry in our Annual Report and Accounts each year.

All partnerships with the medicines industry will be subject to a written agreement that is signed by either the Chief Executive or the Head of Research.

All decisions about whether to enter into a partnership with or accept sponsorship from the medicines industry on a particular project will be consistent with the TSA's policy on accepting donations.



Policy approved by the Board: July 2021
Policy due for review: July 2024

