

Working With Pharmaceutical Companies Policy

Background

Tuberous Sclerosis Complex New Zealand's vision is a world where every family affected by Tuberous Sclerosis (TSC) is empowered by the best treatment, information and support.

Pharmaceutical companies are one key party in the search for better treatments, and eventually a cure, for TSC. Working with pharmaceutical companies that manufacture and market drugs and treatments gives us important background knowledge and provide positive networking opportunities.

Pharmaceutical companies are also willing to sponsor and fund certain activities we undertake. TSCNZ, as a charitable organisation, relies on the generosity of its members and donors and on fundraising events to fund our activities. TSCNZ also seeks grants from commercial organisations, government and philanthropic funds. We are committed to developing a variety of long term dependable income sources to fund our work.

However, pharmaceutical companies are not charitable organisations and have different interests from our own, including a direct commercial interest in TSC. We also acknowledge that in many cases, the partnership is not equal, in that the pharmaceutical company has many more resources at its disposal than TSCNZ. For these reasons, we take particular care in how our organisation works with pharmaceutical companies and other for-profit health care providers.

We also acknowledge that, because there are a limited number of treatments for TSC, there are a limited number of pharmaceutical companies with an interest in TSC. TSCNZ is also committed to supporting research that leads to new treatments for TSC.

The purpose of our policy is to provide clear principles and guidance about how TSCNZ works with pharmaceutical companies to achieve our objectives, without compromising our integrity and our ability to support our members. These will ensure that our activities are not in any way influenced by the commercial interests of the for-profit companies we work with.

Policy Review

The TSCNZ Committee will review this policy annually

Principles

- TSCNZ will independently set its own priorities, policies and plans
- TSCNZ is committed to total transparency in all dealings with pharmaceutical companies
- TSCNZ will not endorse individual pharmaceutical products or suppliers of health care services

- TSCNZ will seek to develop relationships with multiple pharmaceutical companies, so as not to develop a special relationship with only one company
- TSCNZ will engage in dialogue with pharmaceutical companies about Tuberous Sclerosis treatments for the betterment of our members.

Practice

1. Openness and Transparency:

- This policy will be published on the TSCNZ website.
- A full list of donations and grants received from pharmaceutical companies will be published in the annual reports of TSCNZ.
- TSCNZ will acknowledge financial support for projects with a statement similar to “This project was funded by an unrestricted grant from <company name>. This company had no influence over the outcomes of this project”.
- TSCNZ will maintain a register of all involvement with pharmaceutical companies which will be available on request the TSCNZ members and the community.
- The TSCNZ Committee will encourage members to raise any concerns about TSCNZ relationship with pharmaceutical companies. These questions and concerns will be discussed at the next committee meeting.

2. Funding of Projects

- All relationships with pharmaceutical companies will be documented in signed memoranda of understanding (MOU). This MOU will have agreed roles and responsibilities clearly defined for all parties.
- TSCNZ will only encourage funding for projects that have been identified as priorities in the regular TSCNZ planning process. These will be projects that align with TSCNZ’s mission and objectives. Projects that are initiated by a pharmaceutical company will be approved by the TSCNZ Committee before they proceed.
- Funding will only be accepted from Pharmaceutical companies where the project has a fixed timeframe and outcome. Funding will not be accepted for ongoing costs of operating TSCNZ.
- TSCNZ will attempt to fund projects by other sources first and only accept money from pharmaceutical companies where other funding requests are unsuccessful or unlikely to be successful.

3. Promotion

- TSCNZ will not endorse any specific drug or treatment. Where possible, when discussing treatments, TSCNZ will refer to a class of drugs (e.g. “mTOR inhibitors”) rather than a specific drug or brand name.
- TSCNZ will not accept or distribute promotional products provided by a pharmaceutical company and will not allow distribution of such products at TSCNZ events.

4. Education

- TSCNZ will keep our key staff and volunteers informed on TSC research, the drug development process and the way the pharmaceutical industry operates.

- b. TSCNZ will work with other members of TSC International and learn from their experiences of working with pharmaceutical companies.
 - c. TSCNZ will seek to ensure that all medical information it publishes are reviewed by the TSCNZ medical advisors, who are independent clinicians.
5. Representing TSC Families
- a. TSCNZ understands that in its role as representing the families affected by TSC in New Zealand that it may be asked to review patient information material to ensure that it has validity and understanding for its audience. TSCNZ will not accept any fee for this service. TSCNZ representatives may, however, be reimbursed for any out of pocket expenses associated with this activity.
6. Other
- a. The TSCNZ Committee will review any offer of hospitality, including travel and accommodation that is provided or funded by a pharmaceutical company.
 - b. The TSCNZ logo and name cannot be used by any pharmaceutical company to promote a product.

References

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2. Herxheimer, A. 2003, 'Relationships between the pharmaceutical industry and patients organisations', *BMJ*, Vol 326, pp 1208-1210
3. Kent, A. 2007, Should patient groups accept money from drug companies? Yes, *BMJ* 2007 ;334:93
4. Consumers' Health Forum & Medicines Australia 2005, Working together. A guide to relationships between health consumer organisations and pharmaceutical companies, Consultation, <https://www.chf.org.au/pdfs/fac/fac-Working-together-guide-2008.pdf>
5. Breast Cancer Care (UK), Policy on working with Pharmaceutical Companies, http://www.breastcancercare.org.uk/sites/default/files/files/pdf/pharmaceutical_policy_sept09.pdf
6. Arthritis Victoria, Relationships with Pharmaceutical Companies Policy, <http://www.arthritisvic.org.au/pages.asp?d=5A4C5A717251477C7008060B0E0800>
7. Cancer Voices Australia, Policy on Collaboration with the Pharmaceutical Industry, <http://www.cancervoicesaustralia.org.au/pdfs/policy/pharmaceutical.pdf>