

IMP Policy

Working with Pharmaceutical Companies

Background

Mission:

To increase quality of life for people with mitochondrial disease (mito) by facilitating cross-border cooperation and collaboration among national patient organisations.

Objectives:

- * To share best practices, information and knowledge, in order to:
 - promote early diagnosis;
 - develop appropriate care pathways;
 - clinically manage the disease;

- * To be an international bridge between patients, clinicians, scientists, industry and policy-makers;

- * To promote and advocate for speedy development of treatments and cures.

In line with its objectives, IMP acknowledges the need to, on occasion, work in collaboration with pharmaceutical companies. Adhering to this policy will ensure that any association is developed transparently and with the upmost integrity.

IMP acknowledges the vital role pharmaceutical companies play in developing treatments and cures for mitochondrial patients, and in helping to improve their quality of life.

Cooperation between industry and patient support groups should be encouraged. Because IMP and its members support a patient's right to treatment, and therefore have an interest in cooperating with companies developing/providing these treatments. The limited means of patient groups must not be exploited by industry and the issues of transparency and confidentiality should be properly addressed.

The International Federation of Pharmaceutical Manufacturers and Associations has guidelines for its members regarding working with patient organisations, to ensure that any collaboration protects the rights both the organisations as well as, most importantly, the patients. Details of these standards can be found at the end of this document.

Examples of working with pharmaceutical companies include providing input from patients' perspective (for no financial return), and being the recipient of financial grants.

IMP is funded through membership fees and receives no structural government funding. IMP does not compete with its members for funds from individuals or grant making organisations. IMP seeks multinational opportunities, either directly for IMP or as part of a consortium with members, which are not obtainable by a single member. This can be in the form of donations from multinational pharmaceutical companies.

Principles

IMP will independently set its own priorities, policies and plans.

IMP is committed to total transparency in all dealings with pharmaceutical companies.

IMP will not endorse individual pharmaceutical products or suppliers of health care services.

IMP will seek to develop relationships with multiple pharmaceutical companies, so as not to develop a special relationship with only one company.

IMP will engage in dialogue with pharmaceutical companies about treatments, cures, prevention and diagnosis of mitochondrial diseases for the benefit of the global mito community.

Practice

1. Openness and Transparency:
 - a. This policy will be published on IMP's website.
 - b. A full list of donations and grants received from pharmaceutical companies will be published on IMP's website.
 - c. A full list of donations and grants received from pharmaceutical companies will be published in IMP's Annual Financial Report.
 - d. IMP 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".
 - e. IMP will maintain a register of all involvement with pharmaceutical companies. This will be available on request to IMP members.
 - f. IMP will encourage members to raise concerns about its relationship with pharmaceutical companies. These questions and concerns will be discussed at the following Board Meeting and put to IMP's members if necessary.
2. Funding Agreements
 - a. 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.
 - b. IMP will only encourage funding for projects that have been identified as priorities within IMP's Strategic Plan and align with IMP's mission and objectives. Projects that are initiated by a pharmaceutical company will be approved by IMP members before being taken any further.
 - c. Funding may involve well-defined projects as well as general donations. General donations must in all cases be unconditional and to be used at the sole discretion of IMP.
 - d. Any funding may not exceed 25% of the annual budget of IMP.

3. Promotion
 - a. IMP will not endorse any specific drug or treatment.
 - b. IMP will not accept or distribute promotional products provided by a pharmaceutical company.
4. Education
 - a. IMP will keep our Board, members, staff and volunteers informed about research into mitochondrial disease.
 - b. IMP will work with its members and learn from their experiences of working with pharmaceutical companies.
5. Representing the mitochondrial community
 - a. IMP understands that in its role of representing the mitochondrial community it may be asked to review patient information material to ensure that it has validity and understanding for its audience. IMP will not accept a fee for this service. IMP representatives may, however, be reimbursed for any out of pocket expenses associated with this activity.
6. Other
 - a. IMP will review any offer of hospitality, including travel and accommodation that is provided or funded by a pharmaceutical company.
 - b. The IMP logo and name cannot be used by any pharmaceutical company to promote a product.

Policy Review

A designated IMP Board Member will be responsible for the execution and of this policy, and will report on it annually to the full Board. The Board will review this policy every 24 months, or sooner if required. (Board member to be confirmed post June 2021 election.)
Version 1: April 2021

Acknowledgement

Thank you to Tuberous Sclerosis Australia, for generously giving permission for IMP to base this policy on one they created. Working together and supporting each other as a rare disease community, allows each organisation to achieve more for the patients they represent.

Pharmaceutical Industry Policies

The International Federation of Pharmaceutical Manufacturers and Associations (IFPMA)
[IFPMA Code of Practice \(2019\)](#)
[IFPMA Note for Guidance on Patient and Patient Organization Interactions](#) (2020)
European Federation of Pharmaceutical Industries and Associations (EFPIA)
[EFPIA Code of Practice on Relationships between Pharmaceutical Industry and Patient Organisations](#) (2021)