



Supporting families affected
by primary and secondary
immunodeficiency

Working with the pharmaceutical industry

Background

Immunodeficiency UK's mission is the advancement of health and the relief of people affected by primary and secondary immunodeficiency and their families and people responsible for their welfare, in particular:

- (a) by providing assistance, advice or guidance in relation to managing their condition and improving the diagnosis of these conditions, their treatment and the quality of life of those affected;
 - (b) promoting awareness and understanding of primary and secondary immunodeficiency within the general public and medical profession in order to better understand these conditions and their impact; and
 - (c) providing a helpline service, events and practical help and advice.
- (2) To encourage and support research into the causes, treatments, prevention, and cures for primary and secondary immunodeficiency, and to publish the useful results of that research.

Pharmaceutical companies are a significant party in the search for better treatments and cures for people with immunodeficiency. Working with pharmaceutical companies that manufacture and market drugs and treatments gives Immunodeficiency UK important background knowledge and can provide positive networking opportunities.

Pharmaceutical companies are also willing to sponsor and fund certain activities that we may want to undertake.

Immunodeficiency UK relies on the generosity of its members and donors and on the proceeds from fundraising events to fund its activities. Immunodeficiency UK also seeks grants from commercial organisations, government, and philanthropic funds, and is committed to developing a variety of long-term dependable income sources to fund its work.

However, pharmaceutical companies often have different interests from Immunodeficiency UK's, including a direct commercial interest in primary and secondary immunodeficiency.

Immunodeficiency UK acknowledges that in many cases the partnership is not equal and that pharmaceutical companies have many more resources at their disposal than itself. For these reasons, Immunodeficiency UK takes particular care in how it works with pharmaceutical companies and other for-profit healthcare providers.

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

Policy review

Immunodeficiency UK will review this policy every two years.

Principles

- Immunodeficiency UK will independently set its own priorities, policies and plans.
- Immunodeficiency UK is committed to total transparency in all dealings with pharmaceutical companies.
- Immunodeficiency UK and its Patient Representative Panel will not endorse individual pharmaceutical products or suppliers of healthcare services.
- Immunodeficiency UK will seek to develop relationships with multiple pharmaceutical companies, so as not to develop a special relationship with only one company.
- Immunodeficiency UK will engage in dialogue with pharmaceutical companies about treatments for the benefit of its members and community.

Practice

1. Openness and transparency:

- a. This policy will be published on the Immunodeficiency UK website.
- b. Details of donations and grants received from pharmaceutical companies will be published in the annual reports of Immunodeficiency UK.
- c. Immunodeficiency UK will acknowledge financial support for projects on its website at with a statement similar to 'In [year] Immunodeficiency UK was a recipient of a donation from [company name]'.
- d. Members of the Immunodeficiency UK Medical Advisory Panel and the Patient Representative Panel will submit a disclosure of interests form annually.

2. Funding of projects:

- a. Immunodeficiency UK will encourage funding for projects that have been identified as priorities in the Immunodeficiency UK planning process. These will be projects that align with Immunodeficiency UK's mission and objectives. Projects that are initiated by a pharmaceutical company will be approved by the CEO of Immunodeficiency UK, in discussion with its Trustees, Patient Representative Panel and chair of the Medical Advisory Panel, before they proceed.

3. Promotion:

- a. Immunodeficiency UK and its Patient Representative Panel will not endorse any specific drug or treatment. Where possible, when discussing treatments, Immunodeficiency UK will refer to a class of treatment rather than a specific drug or brand name.
- b. Immunodeficiency UK will not accept or distribute promotional products provided by a pharmaceutical company and will not allow distribution of such products at Immunodeficiency UK events.

4. Education:

- a. Immunodeficiency UK will keep its key staff and volunteers informed on PID research, the drug development process, and the way in which the pharmaceutical industry operates.
- b. Immunodeficiency UK will work with other members of IPOPI and other organisations and learn from their experiences of working with pharmaceutical companies.
- c. Immunodeficiency UK will seek to ensure that all medical information it publishes is reviewed by the Immunodeficiency UK Medical Advisory Panel (who are independent clinicians) and members of its Patient Representative Panel. Pharmaceutical companies will have no involvement or influence in information

development.

5. *Surveys:*

a. Immunodeficiency UK will work with pharmaceutical companies on pharmaceutical-sponsored patient surveys on the understanding that Immunodeficiency UK has approval over the content and manner of approach to patients, that such surveys are labelled as commercial, that responses are anonymous, and that the information gained is shared with Immunodeficiency UK and its members.

6. *Other:*

a. Immunodeficiency UK will review and declare any offer of hospitality, including travel and accommodation that is provided or funded by a pharmaceutical company to members of its staff and the Patient Representative Panel.

b. The Immunodeficiency UK logo can be used only with permission and prior agreement from Immunodeficiency UK.

c. The Immunodeficiency UK logo and name cannot be used by any pharmaceutical company to promote a product.

d. Immunodeficiency UK will not offer direct third-party access to its database of members.

e. When members of Immunodeficiency UK staff or the Patient Representative Panel are asked by pharmaceutical companies to give an expert patient perspective, it is with the implicit and explicit understanding that in doing so they are not endorsing a company or the products the company offers to patients. To ensure transparency, such presentations will include the following disclaimer: 'In accepting [company name's] invitation to present, I am not endorsing [company name] or the products it offers to patients.'

f. Immunodeficiency UK will not accept sponsorship that:

- Promotes alcohol, tobacco products, firearms or other weapons, or gambling activities
- Promotes unlicensed pharmaceutical products.

Dated 1st April 2021