



Ethical Statement on Donations/Sponsorships

The International Gaucher Alliance (IGA) is an international umbrella group representing the interest of Gaucher patients and those of non-for-profit Gaucher patient groups as well as rare disease groups throughout the world.

Our vision is **'A world where all Gaucher patients have access to the treatment and care they need and there is a possibility of a cure'**.

In our work we rely on the financial support of individuals, companies and grant giving bodies. We fully respect the rights of our supporters to transparent, truthful information about our work, how donations and other income are spent, and how we manage funder's information responsibly.

In all our fundraising activities we pledge to be open, honest, clear, respectful, reasonable and accountable. We are committed to act in the best interest of the Alliance but ultimately in the best interests of Gaucher patients over the world. This ethical statement ensures that we do not compromise on our mission and values when it comes to raising income.

We will do our utmost to solicit and accept funds to advance our objectives and aims, with the presumption that donations/sponsorships are given in good faith and that refusal by the IGA would be only on the strongest grounds.

In soliciting donations and sponsorships the IGA:

- will act with integrity and honesty;
- will not put undue influence or pressure on those from whom we are soliciting funds;
- will base each partnership on mutual respect, with views and decisions of each partner having equal value and
- will not mislead or knowingly give false information.

It is important to maintain our independence, therefore the IGA will only accept funds up to an amount not exceeding 35 % of its annual budget from any one pharmaceutical company. We value our corporate partners and our supporters but cannot allow funders and corporate partnerships to affect our reputation or unduly influence our activities, keeping the interests of people affected by Gaucher disease utmost in our minds. Accepting support from companies will not prevent us calling their actions into question or expressing our views. Nor can we endorse or approve products, services, commercial initiatives, companies or industries.

In accepting or refusing donations, the ultimate responsibility lies with the Board of the IGA. The IGA reserves the right to refuse/return donations or terminate partnerships where the activities of the company, individual or grant making body conflict with our vision, mission, values and overall goal of achieving lasting change for Gaucher patients worldwide, in particular:

- where the activities of a funder are directly opposed to the interests of people affected by Gaucher disease;
- where acceptance of the donation/sponsorship will adversely affect IGA’s reputation or work;
- where acceptance will give rise to actual or perceived conflict of interest;
- where the offer of support is dependent upon the fulfilment of certain conditions/demands placed upon the IGA which are unreasonable or contrary to the interests of people affected by Gaucher disease;
- where money has been raised through illegal or criminal means which could subsequently be challenged in courts;
- where the cost of accepting a donation would be greater than the value of the donation itself (including the possible effects of negative publicity);
- -where the money has been raised through means the IGA does not believe to be morally acceptable;
- -where the activities of the funder are directly hostile to our objectives.

Developed on November 24, 2019

Issue	Description of Change	Approval	Date of Issue
1	New document	Board	Feb 17, 2020