

LHON Collective Policy for Working with the Pharmaceutical Industry

The mission of LHON Collective is to accelerate progress towards a cure for Leber Hereditary Optic Neuropathy (LHON) while improving the lives of people living with LHON.

To best accomplish this goal, LHON Collective will evaluate opportunities to work collaboratively including partnerships and financial support from pharmaceutical companies which can bring benefits to accelerate the development of new drugs and treatments.

Collaboration with all stakeholders

To prioritize finding a cure rapidly, we need to work in collaboration with all stakeholders, including pharmaceutical companies. Our main obligation will be to select those affiliates with care and ensure that we protect the data of any patient that is shared with their explicit consent, and that this data is only used in studies, trials and research that meets the goals of LHON Collective and our patient population. We will be transparent with patients about any formal relationships we make to ensure patient confidence in those relationships, so that the patient is also a formal partner in our shared mission to find a cure.

This LHON Collective Policy for Working with the Pharmaceutical Industry (Policy) therefore lays out how LHON Collective makes decisions to work and partner with the Pharmaceutical Industry. In this document Pharmaceutical Industry/Companies is taken

to stand for all types of pharma, biotech/diagnostic companies, and medical device companies.

About the policy

This Policy defines how LHON Collective works with the Pharmaceutical Industry including the funding we receive and the manner that we form any formal working relationships. It is important that we:

- Maintain our independence and impartiality
- Are transparent, consistent and fair when working with industry
- Maintain our integrity and reputation
- Remain true to our patient-centered approach, putting patients first for every decision we make to ensure best possible outcomes
- Show our commitment to working collaboratively with pharmaceutical companies, alongside other stakeholders to improve patient outcomes
- Remain accountable to our stakeholders and our Board of Directors

Working principles

What are the working principles LHON Collective will abide by when engaging with Pharmaceutical companies?

- Integrity – All partners must be aligned with the values of LHON Collective. We will always act with honesty and integrity in all that we do.
- Independence – LHON Collective will ensure that it maintains independence of its decision making in all partnerships and editorial independence so that we are free to comment both positively and negatively about pharmaceutical companies and their products.
- Transparency – All partnerships must be transparent. We will be clear on which organizations we are working with and why. Details of companies we are working with will be published on our website throughout the duration of a partnership.
- Clarity of purpose: We will only work with pharmaceutical companies on projects that fit with the LHON Collective's strategic goals.

What type(s) of funding would LHON Collective receive from pharmaceutical companies?

LHON Collective currently receives no income from pharmaceutical companies, but is currently engaging with a range of companies that have or are looking to develop drugs or treatments for use in LHON that may develop into LHON Collective receiving funding.

What rules will we apply to income we receive from pharmaceutical companies?

The total level of funding received from pharmaceutical companies on an annual basis shall be on the basis below. This excludes any royalty payments due to LHON Collective.

1) **Core operational funding:** The percentage of funding from Pharmaceutical companies can range up to a percentage of 45% of total income for core expenditure per annum. The rest of LHON Collective's income will consist of voluntary donations from individuals and fundraising activities. We currently also receive no government funding.

2) **Project Activities:** The percentage of funding from Pharmaceutical companies for Project Activities shall be decided on a case by case basis in line with this Policy. There is no requirement for an upper limit on income received from pharmaceutical companies in relation to these costs and no fixed proportion of how much one company can provide. A summary of decisions will be made available on request. LHON Collective maintains decision making independence in relation to project activities through our Board of Directors' guidance and decisions and editorial independence over any materials, meetings and agendas related to the project.

All companies that LHON Collective collaborates with must adhere to their local Code of Practice based on their national and regional geographic location.

The names of all pharmaceutical companies that LHON Collective receives income from will be listed on the LHON Collective website along with the total amount received in the current financial year. All income and all significant donations in kind will also be listed in any statement of accounts created.

What guidelines does LHON Collective follow when working with the Pharmaceutical Industry?

- LHON Collective collaborates with a variety of companies, giving no preference to any one company.
- LHON Collective will not disclose or share any confidential service user data with pharmaceutical companies or their agencies unless explicit consent has been given.
- Our strategy, activities or information will not be influenced by our workings with Pharmaceutical Industry partners/collaborators.
- We will not promote, endorse or favor any particular product.

- A signed written agreement with all companies must be in place which outlines each partner's contribution and responsibilities before LHON Collective accepts funding or agrees to a collaboration
- Prior written approval for the use of the LHON Collective logo or name must be agreed in writing with the LHON Collective CEO. LHON Collective will need to sign off usage of the logo in all instances of use such as marketing collateral, websites, social media to ensure adherence to the LHON Collective brand guidelines.
- LHON Collective retains the right to terminate any working relationship with a company who is seeking to coerce or conform the work of LHON Collective to its agenda.
- We recognise that individuals who work for pharmaceutical companies may wish to fundraise for LHON. Any such fundraising will not influence our work or information provided to people living with LHON.
- LHON Collective will work with members of the Pharmaceutical Industry to share knowledge and expertise. This may involve the participation in Pharmaceutical Industry organized events such as private or public meetings, training events, advisory board meetings and market research events or Pharmaceutical Industry involvement in LHON Collective organized events.
- This Policy does not exclude LHON Collective Board of Directors, advisors, or staff working with or investing in the Pharmaceutical Industry in their private capacity, but external interests must be declared in line with LHON's [Conflicts of Interest Policy](#).